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ABSTRACT

This publication contains a curriculum to prepare nurses for delivery of hospice care for the terminally ill. It provides training manuals for both participant and facilitator in a preservice or inservice Hospice Education Program. Each manual (participant and facilitator) includes nine modules: (1) Hospice Care Concept; (2) Communication Skills; (3) Concepts of Death, Dying, and Grief; (4) Family Dynamics and Family Counseling; (5) Managing Personal and Organizational Stress in the Care of the Dying; (6) Understanding the Process of Dying and the Death Event Itself; (7A) Pharmacology; (7B) Pain and Symptom Management; (8) Interdisciplinary Team; and (9) Ethical and Legal Issues in the Care of the Terminally Ill. The participant manual may contain any or all of the following: purposes and goals, module content, learning objectives, module outline, informational materials and/or articles, learning activities, exercises, and bibliography. The facilitator manual provides a detailed outline of each of the nine modules and a step-by-step description of the methods to be used in module presentation. These instructions include a sequential outline of lecture material, discussion points, large and small group exercises, and audiovisual presentations. Appendixes to the facilitator manual include Guidelines for the Clinical Practicum and Evaluation with pretests, posttests, and evaluation for module, course, teacher, and practicum. (YLB)

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# HOSPICE

## EDUCATION PROGRAM FOR NURSES

Developed Under Contract Number HRA 232-79-0087

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Issued: June 1981

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# FOREWORD

Care for the terminally ill in the United States is undergoing marked and rapid change. The needs of the dying patient for comfort, family, friends, and relief from pain have led to alternative approaches, such as hospice care, for the terminally ill. The recent growth in hospice care and a gap in training programs for health professionals in the area of death and dying evidenced a need for educational programs based on hospice care concepts. Recognizing this need, the Division of Nursing in 1979 contracted with HCS, Inc. of Potomac, Maryland, to undertake a project to examine the components of hospice care and the role of nurses in delivering such care. Implications of changes for nursing care in caring for the terminally ill and needed educational preparation for nurses were to be examined and a curriculum developed to prepare nurses for delivery of hospice care.

This publication presents the developed and tested curriculum, including training manuals for both participant and facilitator. The model curriculum is supported by leaders in the hospice movement. The Division of Nursing feels it will be of great usefulness to the many people involved in education and utilization of nurses for hospice care.

Jo Eleanor Elliott

Jo Eleanor Elliott
Director
Division of Nursing

# PREFACE

In September 1979, the Division of Nursing of the Health Resources Administration contracted with HCS, Inc. of Potomac, Maryland to develop, implement and evaluate an instructional program to prepare Registered Nurses to provide hospice care. This course, the Hospice Education Program for Nurses, represents the final product of that effort and reflects the active involvement of numerous individuals and organizations concerned with hospice care and nursing education.

Dr. O. Marie Henry, the Project Officer for the Division of Nursing, provided her personal support and technical expertise throughout the developmental process of the course. Martha Russell, the Project Director provided consistent leadership in managing the overall project and coordinating the work of content specialists from all over the country.

The project began with an extensive review of the literature on hospice care and with site visits of hospice programs where project staff studied nurse utilization patterns and skill and knowledge competencies required of the hospice nurse. Data from these two sources was utilized by a Technical Advisory Committee to identify priority educational needs of hospice nurses, to determine the content modules of the curriculum, to establish the content areas within each module, and to recommend the allocation of instructional time for each module. The Technical Advisory Committee was composed of the following persons:

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Following the identification of the course modules, content experts were recruited to develop each module incorporating material that addressed the primary knowledge and skill needs of the hospice care nurse. The American Nurses Association, the American Hospital Association, the American Oncology Nurses Association and the Forum for Death Education were particularly helpful in recommending both technical advisory committee members and content specialists with expertise in the major course subject areas. Those content specialists responsible for the design and authorship of each of the nine course modules are listed below:

| | | |
|---|---|---|
| Module I | Hospice Care Concepts | Florence Wald, R.N., M.S.<br>New Haven, CT |
| Module II | Communication Skills | William L. White, M.A.<br>Senior Research Associate<br>HCS, Inc.<br>Potomac, MD<br><br>Cynthia D. Kunz, M.A.<br>Senior Research Associate<br>HCS, Inc.<br>Potomac, MD<br><br>Judith Hogan, R.N., M.S.N.<br>Director, Continuing Education, HCS, Inc.<br>Potomac, MD |
| Module III | Concepts of Death, Dying and Grief | Therese Rando, Ph.D.<br>Naragonsett, RI |
| Module IV | Family Dynamics and Family Counseling | William L. White, M.A.<br>Senior Research Associate<br>HCS, Inc. |
| Module V | Managing Personal and Organizational Stress in the Care of the Dying | William L. White, M.A.<br>Senior Research Associate<br>HCS, Inc. |
| Module VI | Understanding the Process of Dying and the Death Event Itself | Ida Martinson, R.N., Ph.D.<br>Professor of Nursing<br>Director of Research<br>School of Nursing<br>University of Minnesota<br>Minneapolis, MN |
| Module VII-A | Pharmacology | Arthur Lipman, Pharm. D.<br>Associate Professor of Clinical Pharmacology<br>Chairman, Department of Pharmacy Practice<br>University of Utah<br>Pharmacology Consultant<br>Hospice of Salt Lake<br>Salt Lake City, UT |

|  |  |  |
|---|---|---|
| Module VII-B | Pain and Symptom Management | Marilee Donovan, R.N., Ph.D.<br>Chairperson, Medical Nursing<br>Rush Presbyterian St. Lukes Hospital<br>Chicago, IL |
| Module VIII | Interdisciplinary Team Concepts | Jane Isaacs Lowe, M.S., A.C.S.W.<br>Preceptor<br>Department of Social Work Services<br>Mt. Sinai Hospital<br>New York City, NY<br>Instructor<br>Department of Community Medicine<br>Mt. Sinai School of Medicine<br>Marjatta Herranen, R.N., M.S.N.<br>Clinical Specialist<br>Mt. Sinai Hospital<br>New York City, NY |
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The Hospice Education Program for Nurses was field tested and evaluated twice. The first field test was hosted in cooperation with The Catholic University of America in Washington, D.C. This field test was conducted with a group of 26 nurses and nursing educators from 10 states representing a diverse range of hospice care experience and varied levels of educational preparation. The hospitality and support of Dr. Edmund Pellegrino, President of The Catholic University of America, contributed greatly to the success of this first field test.

Following revisions and refinements on four of the nine course modules, a second field test was conducted in cooperation with the University of Minnesota School of Nursing Continuing Education Program. Ms. Carmian Siefert, R.N., M.P.H., Hospice Coordinator of the Hospice of St. Paul, Bethesda Lutheran Medical Center, and Ms. Kitty Smith, R.N., B.S.N., Hospice Coordinator for North Memorial Hospital in Minneapolis provided invaluable assistance in coordinating logistical arrangements for the field test and in supervising the practicum clinical experiences of the field test participants.

The 80 hours of curriculum that make up the Hospice Education Program for Nurses contains both original resource papers developed by the various content specialists and a number of previously published papers that the content specialists have integrated within their modules. We would like to thank the following authors and publishers for permission to reproduce the materials listed below. Further reproduction of these materials is prohibited without specific permission of the copyright holder. Permission to reproduce the following material is greatfully acknowledged:

I. Leonard Pearson & C.M. Saunders for Pearson, Leonard (ed.) Death and Dying: Current Issues in Treatment of the Dying Person, Chapter 3, Saunders, C.M. "Moment of Truth, Care of the Dying Person", Press of Case Western Reserve University, 1969.

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A. Occasional Notes, "Professor Wall's Three Phases of Pain", The New England Journal of Medicine, Vol. 301, 1979, pp 1129-30.

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XIX. The Journal of the American Medical Association for Department of Drugs, A.M.A., "Should Heroin be Available to Treat Severe Pain", JAMA, 240, 15, October 6, 1978.

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# VOLUME I: PARTICIPANT MANUAL

# INTRODUCTION: COURSE OVERVIEW

## PURPOSE

During the past decade, the hospice has emerged as a significant and innovative model for the care of the dying patients and their families. The rapid proliferation of hospice care programs throughout the United States indicates the growing concensus on the need for more effective and humane care of the dying. The nurse holds a critical role in the coordination and provision of hospice care services. In this role, the nurse is frequently called upon to provide services that transcends the knowledge and skills obtained in existing nursing education programs.

The purpose of the Hospice Education Program for Nurses is to prepare nurses to work in hospice care programs. The curriculum is designed to develop the necessary knowledge and skills to enhance the nurse's ability to provide high quality care to dying patients and their families.

## INTENDED AUDIENCE

The Hospice Education Program for Nurses has been designed for nurses who are preparing to work, or are currently working, in hospice care programs. The curriculum has been designed for appropriateness for Associate Degree, Diploma, and Baccalaureate prepared nurses who are currently Registered.

## COURSE GOALS

Upon completion of the Hospice Education Program for Nurses, each participant will:

- Understand the history and philosophy of hospice care and the different models of hospice care currently being provided in the United States
- Acquire communication and counseling skills which enable them to have effective and supportive interactions with dying patients and their families
- Develop a broad understanding of death, dying and grief
- Acquire an understanding of family dynamics and family centered approaches to the care of hospice patients and their families
- Develop personal and organizational strategies for managing professional stress experienced in the hospice care setting
- Increase their understanding of the physiological mechanisms and signs and symptoms of dying

- Acquire knowledge and skills of pain and symptom management in the dying patient

- Develop a framework for interdisciplinary team concepts which will enhance their understanding of and participation in the hospice health care team

- Explore the legal and ethical issues involved in caring for the dying patients and their families.

## INSTRUCTIONAL METHODOLOGY

The instructional methodology combines didactic instruction and experiential learning. Various methods are used to make the learning process most effective: lectures, mediated demonstrations, simulations, task-group exercises, guided group discussions, movies, field trips and individual reading assignments. Learning activities are designed to facilitate large-group and small-group interactions and to provide participants with an opportunity to practice skills they can use on the job. Each module provides adequate time for new information to be presented, analyzed and applied in practice sessions. There is an implicit expectation for active participation of all participants.

## PRACTICUM EXPERIENCE

In addition to the eighty hours of classroom instruction, the Hospice Education Program for Nurses will in most cases (where resources permit) also entail a practicum experience that is to be completed following the classroom instruction. We have found that this practicum experience is particularly important in providing the nurse with a supervised transition into the new knowledge, skills and orientations required to provide high quality hospice care. There are a number of possible designs for this practicum experience. Your instructors will outline the specific expectations and design for your practicum experience.

## EVALUATION

The Hospice Education Program for Nurses has been designed to include up to five evaluation elements:

1. Each participant will take a pre-test at the beginning of the course and a post-test at the conclusion of the course. These tests measure learning gains that have been achieved during the instruction.

2. Participants will receive formal and informal feedback on skill mastery from the instructors during the learning exercisesdispersed throughout the nine modules.

3. Each participant that participates in a clinical practicum will receive a narrative evaluation report from the practicum supervisor.

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4. Each participant will be asked to complete an evaluation of each of the nine modules. This evaluation instrument provides an opportunity to assess the clarity, completeness, organization, utility and presentation of each module.

5. Each participant will be asked to complete an evaluation of the complete Hospice Education Program for Nurses. This evaluation instrument provides an opportunity to comparatively assess the modules and the presentors, rate the organization of the overall program, rate the instructional materials and rate the instructional facilities.

These evaluation tools are designed to enhance the further refinement and improvement in the course.

# MODULE I: HOSPICE CARE CONCEPTS

Participant Manual

DEVELOPED BY

Florence S. Wald, R.N., M.S.

# MODULE I: HOSPICE CARE CONCEPTS

## Purposes and Goals

The purpose of Module I is to introduce the concept and philosophy of hospice to the trainee. The goals of the module are to assist the nurse in:

- Identifying why hospice care is needed for dying patients and their families
- Understanding the rights of patients and families
- Recognizing the multidisciplinary approach of hospice care
- Developing a sensitivity to the physical, psychosocial and spiritual needs of dying patients and their families

## Module Content

The module content includes the following areas:

- Historical review of medical/nursing care in institutions in the United States
- Development of hospices in the 20th century
- Rationale for palliative care
- Assumptions and Principles Underlying Standards for Terminal Care

## Learning Objectives

At the conclusion of Module I participants will be able to:

- Describe why reform of care for dying patients and their families was needed
- Identify the dehumanization of patients which was occurring in traditional institutions before reforms were instituted
- Name two individuals responsible for reform of care of terminally ill patients
- List five forms of hospices which have evolved
- Discuss The Assumptions and Principles of Terminal Care
- Discuss the rights of patients and their families in involvement of care

- State the Assumptions and Principles Underlying Standards for Terminal Care
- Define hospice
- Describe the hospice philosophy of care of the terminally ill

# HOSPICE CARE CONCEPTS

The German sociologist Max Weber recognized that every reform begins with dissatisfaction with an existing system and then with the development of ideas for a new approach. If the ideas are to be kept alive, a tension must develop between idealists who nourish the ideas and policy makers who institutionalize them. Each of these groups is necessary to maintain balance between ideas and realities. The development of the hospice reform can be considered in the framework of Weber's ideas of social change to provide a helpful perspective on its origins and growth.

## SECTION A: WHY REFORM OF CARE DURING A TERMINAL ILLNESS WAS NEEDED

Health care in the twenty years from the beginning of World War II can be characterized as a time of rapid development and sophistication of technology, which sky rocketed costs and encouraged depersonalized care. Up to the 19th century, dying was an integral part of the life cycle, an event in which both the immediate and the extended family were closely involved. The rapid development of technologically-oriented medical care, however, shifted the care of the critically ill from families to medical institutions where new methods for curing and controlling many illnesses promised reprieve from death. The primary emphasis placed by such institutions on the cure of illness diverted the public and the health care community away from the acceptance of the inevitable course of certain diseases and toward further medical and scientific intervention. Major medical centers contributed impressive, but impersonal, technological approaches to the cures of illness. Control over personal fate shifted from the patient and the family to the institution and its workers.

Pathology, rather than people, became central to medical training. Nurses, doctors and social workers, who had been trained and educated in the pre-World War II period to be caring persons, now had to fit into an institutional model of practice which promoted detachment, objectivity, the scientific approach and technological competence. Earlier role models for caregivers who were educated before 1940, such as William Osler, for physicians, Annie W. Goodrich for nurses, and Helen Hull for social-workers, were displaced. Young interns were now trained to be decision-makers, were expected to know what was best for both patient and family. They typically responded to emotional pain with blanket assurances in the belief that patients should rely on the physician's judgment. Diagnosis was increasingly based upon laboratory tests. Assessing the patient's total situation became tangential. Treatment of the disease was vigorous and persistent until the patient died; then, the inquiry into cause and effect was extended by asking the family's permission for an autopsy.

The nurse who had seen him/herself as the doctor's assistant and as the caring person for the patient, now had to monitor increasingly complex and numerous apparatuses. She/he had to keep patients' records in order while nursing care became divided between professional and non-professional nurses so that tasks could be done quickly and inexpensively.

If the nurse attempted to take care of the patient, assist the doctor and manage the setting, the overload was too great and the nurse was frequently in conflict. But when physician's assistants, unit managers, nurses aids and special technicians joined the work force and divided nursing by tasks rather than by patients, the nurse-patient relationship, as well as the nurse-doctor relationship was weakened. Patients rarely saw the professional nurse as responsible for their care. Because the rule was "Doctors answer questions," the nurse learned to evade the repeated, direct, and urgent queries of patients and families by referring them to the doctor. Nurses complained bitterly at their limited role, but felt powerless.

Social workers joined in this conspiracy of silence which removed the patient from a participating role in vital decisions and worked primarily with the family to plan for and deal with the illness, a policy that reinforced both the patient's isolation and the institution's authority. There was often pressure to hasten the discharge of one patient to make the bed available for the next, at the expense of adequate planning and continuity of care.

Quality of life and economic cost were not discussed. No answers were given to such pertinent questions as:

- Does the treatment truly mitigate against the relentless course of the disease?
- Is there risk of introducing side effects even worse than the original disease?
- Does prolongation of life have value for the patient?
- Are choices understood?
- Is there help in reaching necessary decisions?
- As the number of days are extended, what will happen to the patient and the family as a social unit, and what may happen to them spiritually?

Before 1970, the question of how long should efforts to sustain and prolong life continue, when the possibility of cure was exhausted, was rarely asked or discussed.

A major strain on medical centers was the conflicting demands and tensions of teaching, research and intensive care. The dying patient was enmeshed in that struggle. A patient who was no longer useful for teaching medical students might occasionally be suitable for research and so could remain in the hospital, but without one of these roles patients were sent to nursing homes or returned to a family unprepared and often ill-equipped to offer the necessary care.

Community resources and outpatient services were inadequate for the demand, leaving patient and family with hopeless choices and essentially abandoned, at the end, by most professional caregivers. Visiting nurse agencies did not have enough staff to meet all the patients' needs at any hour of day or night and doctors no longer made home visits.

Extended-care facilities posted other problems. At worst, as nursing home scandals later revealed, many such facilities were far below standards, although they were making large profits. At best, and even in nursing homes that provided adequate life-sustaining care, staff and programs were too limited to improve the dying patient's condition or to meet the needs of patients' families.

Treatment of physical pain was limited to a small selection of analgesics very sparingly used by attending physicians. Increased tolerance and fears of addiction motivated the withholding of narcotics until the very end, when an assortment of sedatives and analgesics brought the patient's life to a close in unresponsive silence.

Social workers, on the sidelines, were frowned upon when they voiced the emotional pain, the lonely feelings of dying patients and the distress of their families. They were often accused of creating the pain and distress instead of being their messenger.

Any mention of the idea that patients had fears and might want to express them was met with frozen silence. What happened to the patient after being removed from the hospital was outside the hospital's responsibility; its role was to treat illnesses, not people, so that, in effect, the person was non-existent.

In short, advancing surgery in brain, heart and blood vessel, as well as the use of implants, transplants, antibiotics, steroids, intensive radiation and radioactive substances made medical care, especially for patients with cancer extremely complex. Reaching for recovery was the unending goal. Caregivers became specialized, institutions complex, and the whole health care system was broken into segments: tertiary medical centers, community hospitals, extended care institutions and home care agencies. The focus of caregivers was on pathology, biochemistry, hydraulic and mechanical engineering and the patient as a human being was difficult to visualize. Doctors felt that patients could not understand the complex problems and that they didn't have enough knowledge to participate in decisions. Doctor-patient relationships weakened, inter-disciplinary collaboration was insufficient. Nurses could see what was happening but felt powerless.

## SECTION B: THE BEGINNING OF REFORM

### Reactions Against Dehumanization

It was in this climate of dissatisfaction and revolt that the ideas of Dr. Cicely Saunders in London and Dr. Elisabeth Kübler Ross in Chicago began to be heard. Both had a significant impact on what was to come.

What had been taboo in 1958 became possible in 1960. The concern for civil and human rights for blacks, women and the oppressed in Vietnam, the third and fourth worlds, and at home, spread to medical centers through medical and nursing students, and even doctors and nurses who brought these deep concerns with them into medical institutions. A subtle, yet marked, reaction to prevailing treatment surfaced in the United States, with more professionals encouraging patients to express what they felt. Customary attitudes not only were challenged but were beginning to change. The rights and roles of patients and the responsibility and accountability of caregivers, were discussed and reformulated by individuals, institutions professional societies. The prestigous and powerful American Hospital Association challenged the physician's "right" to withhold an unfavorable diagnosis or a poor prognosis from the patient and to prescribe treatment without discussing alternatives with patients. The rights of patients called for accountability and responsibility on the part of all caregivers.

It was realized at last that when patients understood the problem and helped in decisions, they could cope more effectively with the illness and could collaborate with caregivers.

The nursing process, proposed by Ida Orlando, R.N., helped nurses to focus, or tune in, on what the patient was feeling and thinking about illness and treatment, while perceiving and understanding their own reactions as well. Caregivers began to get answers to such questions as:

- Where is the money coming from to pay for a catastrophic illness with months of expensive hospitalization?
- How will the teenage sons of a widow fend for themselves after her death?
- Who will cook for a surviving husband and son after the wife and mother dies?

The fact that the patient's illness and death made waves in the immediate family and that professionals were needed to help family during the illness and the bereavement was finally coming to be recognized.

Organizations such as The Society for Health and Human Values were founded to examine and redefine the obligations of caregivers to patients, and to explore the necessity for each discipline to share the work of patient care as a team participant. Members included caregivers, social scientists, funeral directors, teachers, philosophers and non-professionals who had learned through their own experience about the problems involved with death and dying. New and specialized journals included Omega in 1971, Archives of The Foundation of Thanatology in 1969, and The Journal of Thanatology in 1971. Patients and families also established their own forums (Make Today Count, Widow to Widow, the Society of Compassionate Friends) in order to give support to one another, make their needs known and see that their needs were met.

Despite many differences in their approaches two prominent reformers, Elisabeth Kübler Ross and Cicely Saunders, were concerned with and focused upon patients and what they wanted for themselves.

In 1965, Dr. Saunders gave the annual Sybil Palmer Bellos lecture at the Yale New Haven Medical Center at the invitation of the Yale School of Nursing. This lecture "The Moment of Truth: Care for the Dying Person: was subsequently published as one in a group of papers by Leonard Pearson for the Press of Case Western Reserve University. The central theme of the lecture was the idea that "...it is the patient who is or who should be in the center. The question is his because it is his situation and he is the person who matters." (p. 49)

Dr. Saunders had prepared herself as a nurse (completing her work at Oxford during the war years of the early forties), a social worker and as a physician. Once she realized that she wanted to care for persons facing terminal illness, she prepared herself in each one of these disciplines by both happenstance and design: a bad back made it difficult for her to perform nursing care, so she then went on to social work. But once she realized where her interests lay, and recognized the limits on her power within the health care system, she went to medical school at the St. Thomas Hospital in London. After her medical training was completed, she had seven years of experience at two hospices in London (one had an Anglican foundation, and the other a Catholic), St. Lukes and St. Josephs, and full responsibility for more than forty patients at St. Joseph's who had come there after active treatment for their malignant disease and had been abandoned. This clinical experience was coupled with a systematic study and trial of drugs for the relief of pain.

When Dr. Saunders came to New Haven and Yale for a second visit, land had been purchased, the building designed and construction was about to begin on St. Christopher's Hospice. By that time she was well seasoned, a proficient clinician and a believer that, in her practice, the patient's care came first, the work second. She remarked: "Since our work at St. Joseph's is completely person centered, the criterion of success is not how our treatment is working, but how the patient is, what he is doing...what he is being in the face of physical deterioration." (p. 51).

Dr. Saunders' plans for St. Christopher's Hospice in London, which opened in 1967, offered the terminally ill a setting and treatment with an interdisciplinary approach. With medications and psychosocial support, patients improved, were alert and remained symptom-free until the end. The diagnosis of pain was made through meticulous assessment of patients' physical and psychological problems. Medications prescribed took into account the effect of one drug on another and were given to prevent pain rather than to treat it. The patient's family was included in care and was encouraged to take an active part in the care. Family members were given support, assistance and guidance both during the patient's illness and after the patient died.

Dr. Saunders recognized the physical environment as being as important a therapeutic tool as expert medical management. The most important elements of the environment include the atmosphere of attention, security, hospitality, a confident sense of strength and, peace and recognition of the patient and family as a full-time concern.

Dr. Saunders' profound belief in Christianity was her own spiritual foundation, which she considered as important as her expertise in the practice of modern medicine.

> "When Christ was facing death in the Garden of Gethsemane, He said to His disciples, 'Watch with me.' This is the attitude of mind and heart in which we must approach the dying so that we may try to learn from them and give to them." (Saunders, "And From Sudden Death," Frontier [Winter 1961]).

While she emphasized the importance of some form of spiritual support for the terminally ill and their families, she never insisted that it must be the same as her own. She regarded technology as an instrument, not a master, and stressed that it is the quality of life that is crucial.

Throughout her planning for St. Christopher's, she was oriented to the present and to society as it was and was becoming. Her own skills as a physician were kept totally current and her understanding of the work of other professionals complete. Mrs. Verena Galton, who was to become the Matron at St. Christopher's, worked closely with Dr. Saunders as the architectural design and operations of the hospice were formulated.

While St. Christopher's was being planned and built in the early 1960's, Dr. Saunders came frequently to the United States to gather ideas, especially from the Hawthorne Dominican Sisters, Cancer Care, Inc., Calvary Hospital, City of Hope, and Youville, as well as from the medical centers where active therapy toward cure is given. In return, she discussed her approach to palliative treatment and holistic care and made herself available to help planners here.

With the help of others, among them the psychiatrist Colin Murray Parkes of the Tavistock Clinic, she also included the family and the caregivers as part of the total responsibility. In the 20 years of her work, she has always cared for patients, while at the same time writing, teaching, planning and consulting.

Dr. Saunders' way of approaching patients, listening in order to learn from them, became the basis of her method of teaching others and of presenting her program to potential donors and to policy makers. She felt that no one could present the patient's needs and situation better than the patient. Many persons, including myself, went to St. Christopher's for a work period. In the first five years, there was no formal instruction; rather, we worked informally and side by side with the nursing staff as they could use our help. The greatest proportion of our time, however, was spent being with patients and families, hearing what they had to say. Nurses, medical students, social workers, doctors and clergy were all treated equally.

Those who came back, after working with Dr. Saunders, to the United States and Canada to improve the care of the terminally ill in their own communities took many different paths while the word "hospice" was usually used to describe care of the terminally ill that includes spiritual and psychosocial help as well as medical treatment, the term refers, as well, to a kind of care that can be given in a variety of ways. The word was not originally intended to be restricted to one meaning or type of care only.

Thus, five forms of hospice care evolved:

- Home care services
- Hospice teams in hospitals
- Palliative care units in hospitals
- Hospices with hospital affiliations
- Completely autonomous hospices

An example of the first type was the Hospice of Marin in Kentfield, California, primarily providing home care, although staff also participated in care of patients in several hospitals in that region. At the Hospice of St. Luke's Hospital Center in New York City, an interdisciplinary team of health professionals and clergy shared caregiving with the staff of any hospital unit to which a patient with a diagnosis of metastatic cancer were assigned. The Reverend Carleton J. Sweetser adapted the principles of St. Christopher's to fit this acute-care medical center: since "hospice patients" are in the same rooms with other hospital patients, professional colleagues can see hospice care at work. The palliative care unit created by Dr. Balfour Mount at the Royal Victoria Hospital in Montreal is a separate unit within the hospital, with an interdisciplinary approach and a home care team. Hospice, Inc., in Greater New Haven, is an independent hospice that began by providing home care while the building to house inpatient facilities was being planned and constructed.

While the influence of Dr. Saunders and other English professionals, spread to North America, Dr. Elisabeth Kübler-Ross, a psychiatrist at the University of Chicago Medical School, had also begun working with the terminally ill. While still a very young woman, she had worked with persons displaced during World War II. Death, dying and destruction were, thus, familiar events to her. She became a psychiatrist involved in the teaching of divinity students at the University of Chicago. When they asked her for help in talking with patients facing death, she quickly amassed innumerable interviews with dying patients. Her courses were extended to nurses and medical students and soon she was a sought-after lecturer, traveling all around the United States and encouraging caregivers, especially nurses, to listen to what the dying were saying.

She perceived the human response to imminent death as a series of stages: denial, anger, depression, bargaining and finally acceptance. Her book, On Death and Dying, published in 1969, quickly became a best seller and still sells widely. Her ideas were not appreciated, however, by her colleagues at Chicago; her unorthodox work almost cost her her academic appointment.

Dr. Kübler-Ross encourages patients and caregivers to speak with one another and share how they feel: "...not up here (pointing to her head) but down here, in your gut." She is deeply concerned about the feelings of the caregiver and about the burden of the intense relationships with the dying patient. Although her recent controversial focus on "life after life," and her interest in out-of-body experiences, have caused a rift with colleagues in the field of death and dying, she has motivated many caregivers to work in this field, is still in demand as a lecturer in this country and abroad, and has already founded one teaching center, Shanti Nilaya.

While other Shanti Nilayas are being planned here and abroad, her interest has broadened to encompass a variety of life situations that cause stress. Her writings, lectures and clinical work have helped make the words "death" and "dying" less terrifying. Dr. Kübler-Ross is deeply concerned about and emphasizes the uses of psychic powers, psychodrama, psychic healing and says that she has found evidence of life after death.

## SECTION C: CURE AND PALLIATIVE CARE

If one takes a document such as The Assumptions and Principles of Terminal Care, that defines the problems and the nature of care, the patient, the family and the caregiver can become lifeless. If on the other hand, one thinks of them in the terms of patients and persons we have known, The Moment of Truth, the vitality and the reality can be restored to an otherwise sterile document.

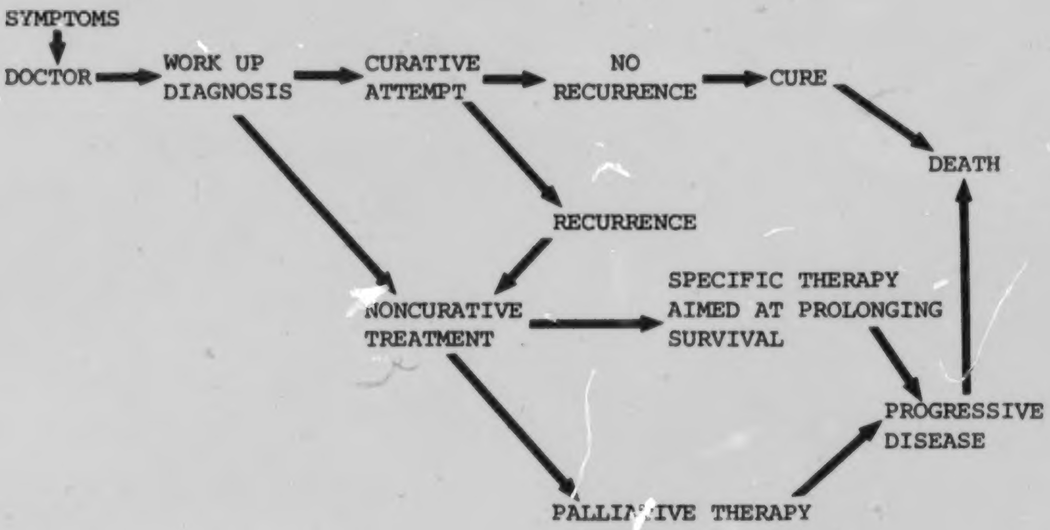
The Assumptions and Principles of Terminal Care was developed over a two and one half year period, from June 1977 through January 1978, by an interdisciplinary group of practitioners and social scientists who came from Canada, England, Sweden and the United States, to work together at regular intervals. The aim of the document is "...to aid those who have initiated or are planning programs for the terminally ill" so that each institution can develop its own standards. The group is prepared to review this document at regular intervals (every eighteen months) to incorporate new ideas. For example, work is now underway to develop a section on bereavement.

The introduction discusses one of the most important issues we currently face, the openness and interchange between the two systems of cure and palliation:

> There is agreement that patients with life threatening illnesses, including progressive malignancies, need appropriate therapy and treatment throughout the course of the illness.
>
> At one stage, therapy is directed towards investigation and intervention in order to control and/or to cure such illness and alleviate associated symptoms. For some persons, however, the time comes when cure and remission are beyond the capacity of current curative treatment. It is then that the intervention must shift to what is now often termed 'palliative treatment,' which is designed to control pain in the broadest sense and provide personal support for patients and family during the terminal phase of illness. In general, palliative care requires limited use of apparatus and technology, extensive personal care and an ordering of physical and social environment to be therapeutic in itself.
>
> There are, as it were, two complementary systems of treatment which may often overlap. One system is concerned with eliminating a curable disease and the other with relieving the symptoms resulting from the relentless progress of an incurable illness.
>
> There must be openness, interchange and overlap between the two systems so that the patient receives continuous appropriate care. The patient should not be subjected to aggressive treatment that offers no real hope of being effective in curing or controlling the disease and may only cause him further distress.
>
> Obviously, the clinician must be on the alert for any shifts that may occur in the course of a terminal illness, which make the patient again a candidate for active treatment.
>
> Patients suffer not only from inappropriate active care, but also from inept terminal care. This is well documented by studies that only confirm what dying patients and their families know at first hand.

These principles have been prepared as an aid to those who have initiated or are planning programs for the terminally ill in delineating standards of care.

Dr. Krakoff, of the Vermont Regional Cancer Center, has diagrammed this progression:


SYMPTOMS
DOCTOR
WORK UP DIAGNOSIS
CURATIVE ATTEMPT
NO RECURRENCE
CURE
DEATH
RECURRENCE
NONCURATIVE TREATMENT
SPECIFIC THERAPY AIMED AT PROLONGING SURVIVAL
PROGRESSIVE DISEASE
PALLIATIVE THERAPY

Krakoff, 1977
Vermont Regional Cancer Center
8-22-77

It is important to note that while we comforters have been developing palliative treatment, intenstive treatment for cancer has also changed. Early diagnosis has become more reliable and the relative values of surgery, radiation, and chemotherapy have been reassessed. There is increasing candor among health professionals about what we know and don't know, and physicians are coming to be expected to share what they know and to share decisions with patients and families. But as the document observes, health care services customarily lack coordination and so the organizational structure must provide links with existing health care professionals in the community.

During the two-year course of the Nurse's Study of the Dying Patient (1969-1971) at Yale, our relationships with other agencies took place informally, involving many agencies on an ad hoc basis. In the case, for example, of Arturo Maestro it was done at a distance. The tertiary medical center was in one city, 40 miles away from the city where Mr. Maestro lived. The visiting nurse, the private physician, the state welfare agent, the Catholic social work agency and the community hospital were involved in helping him to come home. The research unit staff in the tertiary medical center, which had worked so hard to reverse the downhill cause of his disease, was reluctant to see Mr. Maestro leave the hospital. They felt that he had no chance on the outside, and that their hard work would go down the drain.

There can be considerable strain between the two groups of caregivers when a patient is shifted from curative treatment to palliative treatment or from palliative treatment to intensive treatment. It manifests itself in blame, guilt and mistrust before and during the referral process. After the referral, those taking on the care can feel abandoned by and estranged from those who gave it up. Attempts to keep the relationship open often generate resistance.

It is painful for caregivers who have put their hearts, souls, elbow grease and reputations as experts into the care they know best, to turn the care of the patient over to others with a different approach.

Before the study ended we found ways to ease the tension and curb the withdrawal. Excerpts from the study illustrate how the patients, families, and caregivers felt and their mutual need for understanding, support information.

For example, Mr. Arturo Maestro did not have cancer, but he had had extensive intestinal surgery: one-fourth duodenum, entire jejunum and ileum as well as the ascending colon and hepatic flexure had been removed. The surgeon had faced a no-win decision during the operation when he found that the blood supply to the intestines was cut off by clots and caused the intestinal tract to necrose.

For six weeks a devoted team of nurses, doctors and dietitians in a clinical research unit maintained him on intravenous fluids well-laced with electrolytes, proteins and sugars, while they made repeated attempts to devise food that was palatable and digestible. Regulating his underlying heart disease, preventing dehydration, keeping electrolyte balance and controlling diarrhea meant endless hours of work and ingenuity in finding new approaches.

The team was in touch with space program researchers who were then preparing foods for astronauts to use on their voyages. A formula was devised to give Mr. Maestro a 1500-calorie diet consisting of fat in the form of medium-chain triglycerides, carbohydrates as wheat starch flour, and protein in the form of an amino-acid mix. It was gagging to smell, let alone taste. Despite dietitians' imaginative efforts to mask the flavor, Mr. Maestro couldn't keep it down, and vomiting was an added problem.

In the beginning, the staff had assumed that long-term survival was a possibility, so they were very aggressive in attempting the change from intravenous to oral feeding. At the time of our first meeting around the referral, the physician in charge said he had come to realize that: he is not going to be able to do this successfully and the less we unnecessarily prolong his survival, the better.

Attempts to solve the problem investigatively had come to a dead end. This also meant that the number of days he could be cared for in a reasearch unit bed had also come to an end. The social worker had already been asked to find some setting where Mr. Maestro could have continuous intravenous fluids. The only setting that would accept him was one of two chronic disease hospitals in the state. The nearest was thirty miles from his home, reachable only by private car.

As we were to discover later, time to take care of every detail is of great importance. Time and working together is also needed to develop mutual confidence, and additional strain can also develop when, in the end, the treatment devised doesn't work.

The shoe was on the other foot when, five months later, Mr. Maestro went to the doctor's office for his bi-monthly checkup. The doctor expressed shock at how thin, dehydrated and jaundiced he had become. I felt acute guilt. Mr. Maestro was then persuaded by his son and his private physician to go to a tertiary medical center in another city for hyperalimentation. His wife and son went on the train with him but then left him in that strange hospital and strange city. He had a massive coronary attack and died three days after admission.

Then I was the one to feel angry at those who didn't understand him as a courageous, fine man with a loving family he loved and for whom he cared. In the ultimate discharge note that came in the mail, the physician who cared for him there wrote bitterly that he and the family had broken every rule in the hospital, disrupted the ward and that, under the circumstances, the heart attack was understandable. But they hadn't seen him, as we had, getting the first look at his grandchild born in the same hospital where he was a patient, presiding at the christening feast, or sitting in a deck chair at his daughter's home in the woods, a spacious, solid, brick house that he and his son-in-law had built with their own hands.

This close look at our own response to being on the receiving end of a change in settings and treatment gave an unvarnished view of caregivers' investment in the treatment of choice and the feelings with which to be dealt. From there on we had only one way to go: up. Sharing decisions, giving support, pacing ourselves so that everyone involved could adjust, overlooking rebuffs, enhancing up our competence, and admitting our own weaknesses began to change the referral process from a battle to a collaboration.

# ASSUMPTIONS AND PRINCIPLES
# UNDERLYING STANDARDS FOR
# TERMINAL CARE

Formulated by the International Work Group
on Death, Dying, and Bereavement

There is agreement that patients with life-threatening illnesses, including progressive malignancies, need appropriate therapy and treatment throughout the course of illness. At one stage, therapy is directed toward investigation and intervention in order to control and/or cure such illness and alleviate associated symptoms. For some persons, however, the time comes when cure and remission are beyond the capacity of current curative treatment. It is then that the intervention must shift to what is now often termed "palliative treatment," which is designed to control pain in the broadest sense and provide personal support for patient and family during the terminal phase of illness. In general, palliative care requires limited use of apparatus and technology, extensive personal care and an ordering of the physical and social environment to be therapeutic in itself.

There are two complementary systems of treatment, which may often overlap. One system is concerned with eliminating a curable disease and the other with relieving the symptoms resulting from the relentless progress of an incurable illness. There must be openness, interchange and overlap between the two systems so that the patient receives continuous appropriate care. The patient should not be subjected to aggressive treatment that offers no real hope of being effective in curing or controlling the disease and may only cause the patient further distress. Obviously, the clinician must be on the alert for any shifts that may occur in the course of a terminal illness that make the patient a candidate for active treatment again. Patients suffer not only from inappropriate active care but also from inept terminal care. This is well documented by studies that only confirm what dying patients and their families know first-hand. The following principles have been prepared as an aid in delineating standards of care for those who have initiated or are planning programs for the terminally ill.

## GENERAL ASSUMPTIONS AND PRINCIPLES

| ASSUMPTIONS | PRINCIPLES |
|---|---|
| 1. The care of the dying is a process involving the needs of the patient, family and care-givers. | 1. The interaction of these three groups of individuals must constantly be assessed with the aim being the best possible care of the patient. This cannot be accomplished if the needs of family and/or care-giver are negated. |

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|---|---|
| 2. The problems of the patient and family facing terminal illness include a wide variety of issues--psychological, legal, social, spiritual, economic and interpersonal. | 2. Care requires collaboration of many disciplines working as an integrated clinical team, meeting for frequent discussions with a common purpose. |
| 3. Dying tends to produce a feeling of isolation. | 3. All that counteracts unwanted isolation should be encouraged. Social events and shared work that include all involved should be arranged so that meaningful relations can be sustained and developed. |
| 4. It has been the tradition to train care-givers not to become emotionally involved, but in terminal illness the patient and family need to experience the personal concern of those taking care of them. | 4. Profound involvement without loss of objectivity should be allowed and fostered, with the realization that this may present certain risks to the care-giver. |
| 5. Health care services customarily lack coordination. | 5. The organizational structure must provide links with health care professionals in the community. |
| 6. A supportive physical environment contributes to the sense of well-being of patients, of families and of care-givers. | 6. The environment should provide adequate space, furnishings that put people at ease, the reassuring presence of personal belongings and symbols of life cycles. |

## PATIENT-ORIENTED ASSUMPTIONS AND PRINCIPLES

| ASSUMPTIONS | PRINCIPLES |
|---|---|
| 1. There are patients for whom aggressive curative treatment becomes increasingly inappropriate. | 1. These patients need highly competent professionals, skilled in terminal care. |
| 2. The symptoms of terminal disease can be controlled. | 2. The patient should be kept as symptom free as possible. Pain should be controlled in all its aspects. The patient |

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| | must remain alert and comfortable. |
| 3. Patients' needs may change over time. | 3. Staff must recognize that other services may have to be involved but that continuity of care should be provided. |
| 4. Care is most effective when the patient's life-style is maintained and philosophy of life is respected. | 4. The terminally ill patient's own framework of values, preferences and outlook on life must be taken into account in planning and conducting treatment. |
| 5. Patients are often treated as if incapable of understanding or of making decisions. | 5. Patients' wishes for information about their condition should be respected. They should be allowed full participation in their care and a continuing sense of self-determination and self-control. |
| 6. Dying patients often suffer from helplessness, weakness, isolation and loneliness. | 6. The patient should have a sense of security and protection. Involvement of family and friends should be encouraged. |
| 7. The varied problems and anxieties associated with terminal illness can occur at any time of day or night. | 7. Twenty-four-hour care must be available seven days a week for the patient and family where and when it is needed. |

## FAMILY-ORIENTED ASSUMPTIONS AND PRINCIPLES

| ASSUMPTIONS | PRINCIPLES |
|---|---|
| 1. Care is usually directed toward the patient. In terminal illness the family must be the unit of care. | 1. Help should be available to all those involved--whether patient, relation, or friend--to sustain communication and involvement. |
| 2. The course of the terminal illness involves a series of clinical and personal decisions. | 2. Interchange between the patient and family and the clinical team is essential to enable an informed decision to be made. |

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|---|---|
| 3. Many people do not know what the process of dying involves. | 3. The family should be given time and opportunity to discuss all aspects of dying and death and related emotional needs with the staff. |
| 4. The patient and family need the opportunity for privacy and being together. | 4. The patient and family should have privacy and time alone, both while the patient is living and after death occurs. A special space may have to be provided. |
| 5. Complexity of treatment and time-consuming procedures can cause disruption for the patient and family. | 5. Procedures must be arranged so as not to interfere with adequate time for patient, family and friends to be together. |
| 6. Patients and families facing death frequently experience a search for the meaning of their life, making the provision of spiritual support essential. | 6. The religious, philosophical and emotional components of care are as essential as the medical, nursing and social components, and must be available as part of the team approach. |
| 7. Survivors are at risk emotionally and physically during bereavement. | 7. The provision of appropriate care for survivors is the responsibility of the team who gave care and support to the deceased. |

## STAFF-ORIENTED ASSUMPTIONS AND PRINCIPLES

| ASSUMPTIONS | PRINCIPLES |
|---|---|
| 1. The growing body of knowledge in symptom control, patient- and family-centered care, and other aspects of the care of the terminally ill is now readily available. | 1. Institutions and organizations providing terminal care must orient and educate new staff and keep all staff informed about developments as they occur. |
| 2. Good terminal care presupposes emotional investment on the part of the staff. | 2. Staff needs time and encouragement to develop and maintain relationships with patients and relatives. |

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|---|---|
| 3. Emotional commitment to good terminal care will often produce emotional exhaustion. | 3. Effective staff support systems must be readily available. |

# THE HOSPICE MOVEMENT AS A HEALTH CARE REFORM

Florence S. Wald, Zelda Foster, Henry J. Wald

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In the last two decades public interst has brought about open discussion of how death touches all, the treatment and cure of the terminally ill, and how patients and their families can be helped. Such concern and interest have led to the development of the health care reform called the hospice movement, which comprises an array of services--home care, special hospital programs, and new autonomous institutions--to care for the terminally ill. The movement stemmed from increasing dissatisfaction with so much technological care and so little concern for human beings with life-threatening and life-terminating illness; it is searching for a unified approach to life and death that will combine scientific medical knowledge with human and spiritual concerns; and its character has been shaped by the vision, values and skills of a few charismatic leaders and many committed followers.

As the movement continues to develop, interdisciplinary groups in a variety of communities are launching new services, creating new institutions, or revising existing services. In 1975, three institutions were giving care. Three years later, 78 were known to be giving care, and 213 others were planning services.[1] More than 1,000 persons attended the meeting of the National Hospice Organization in Washington, D.C., in October 1978.

But, however, enthusiastically the hospice movement has been endorsed and however rapidly it has spread, it is not without its personal, professional, philosophic, and political problems; the reform has now reached a critical stage. It will take both time and experience to formulate the principles underlying this reform in health care and for the professionals involved in it to develop the necessary expertise; the hospice concept needs a solid base before it can be integrated into the established health care system. Time is also needed to gather facts, consider and test alternative plans, and establish a sense of community within each setting.

Compounding the difficulties is the fact that hospice practitioners are at risk of being distracted from their original goals by the vast army of professional health workers, consumers, journalists, entrepreneurs, political strategists, management consultants, and fund raisers who, suffused with zeal and a sense of driving mission, have been drawn to the movement. In addition, the hospice movement must contend with the inertia of existing institutions, as well as with the problems of governmental licensing and of finding public and private moneys for capital and operational funds. It must also develop a sound internal organization and a smoothly functioning relationship with the other institutions in the total system.

Finally, a balance must be struck between the ideals of the reform, on the one hand, and political and economic realities, on the other, since the way the reform is eventually integrated into the health care system will determine its ultimate scope, quality, and longevity. As Max Weber has pointed out, every reform begins with dissatisfaction with an existing system and the subsequent development of ideas for a new approach.[2] If the ideas are to be kept alive, if a balance is to be maintained between ideals and realities, then a tension must develop between the idealists who nourish the ideas and the policy makers who institutionalize them.

## THE BEGINNINGS

In the 19th century, dying and death were recognized as an integral part of the life cycle, and both the immediate and the extended family were closely involved.[3] But there was a gradual shift away from this approach and, until relatively recently in this century, health care in this country has been characterized by sophisticated technology, high costs, and increasing depersonalization. Control over personal fate has shifted from the patient and the family to the institution and its staffs--especially the medical staff. Emphasis is on cure, not care; pathology, rather than people, has become central. While at the end of the nineteenth century a few non-profit and specialized institutions were founded to care for dying patients who were indigent--among them the seven homes of the Order of Hawthorne Dominicans, Calvary Hospital in New York City, and Youville Hospital in Cambridge, Massachusetts--none of them challenged or involved the existing care system.

Gradually, however, a subtle yet marked dissatisfaction with prevailing treatment surfaced and gave rise to the present hospice reform. Originally conceived of as care of the terminally ill that included spiritual and psychosocial help for patient and family as well as medical treatment, the hospice idea has not only challenged customary attitudes but brought about some changes in them. The rights and roles of patients, the responsibility and accountability of caregivers, have been discussed and reformulated by individuals, institutions, and professional societies. The prestigious and powerful American Hospital Association, in its Patients' Bill of Rights, has challenged the physician's "right" to withhold an unfavorable or a poor prognosis from the patient or to prescribe treatment without discussing alternatives with patients. It is now realized that when the patient understands the problems and helps in decisions, he can cope more effectively with treatment.

The literature reflects this change. When The Meaning of Death--a series of essays on death and dying written by anthropologists, philosophers, psychiatrists and theologians and edited by Henry Feifel--was published in 1959, it marked the beginning of a new era when the subject of death would be seriously studied.[4] Within 15 years the yield of a Medlar search on the subject expanded from a few hundred to a few thousand citations. New societies concerned with terminal illness were formed, their members including caregivers, social scientists, funeral directors, teachers, philosophers, and nonprofessionals who have learned through their own experience about the problems involved with death and dying and want to share their ideas with others. New journals have emerged, and patients and families have now established their own forums (Make Today Count, Widow to Widow, the Society of Compassionate Friends) in order to support one another.

The first and most powerful impetus to the hospice movement was provided by the work of Cicely Saunders and Elisabeth Kübler-Ross. Dr. Saunders, founder and medical director of St. Christopher's Hospice in London, recognized that the physical and social environment was as important a therapeutic tool as expert medical management. Her profound belief in Chritianity was her spiritual foundation, which she considered as important as her expertise in medical practice.[5]

Similarly, Dr. Kübler-Ross, formerly on the faculty of the University of Chicago Medical School, added a new dimension to the care of the terminally ill with her perception of the human response to imminent death as a series of stages: denial, anger, depression, bargaining, and finally acceptance. She has motivated many caregivers to work in this field, and her writings, lectures, and clinical work have helped make the words "death" and "dying" less terrifying. Her book, On Death and Dying, published in 1969, quickly became a best seller and still sells widely.[6]

## A NEW KIND OF CARE

Today hospice is broadly conceived as referring to a kind of care for the terminally ill and their families that can be given in a variety of ways and under different kinds of auspices. In fact, five forms of hospice care have now evolved: 1) home care services, 2) hospice teams in hospitals, 3) palliative care units in hospitals, 4) hospices with hospital affiliations, and 5) completely autonomous hospices. The International Work group on Death, Dying and Bereavement advocates a diversity of approaches in providing care, as long as the basic principles that it has promulgated are observed.[7] The Connecticut Hospice in greater New Haven, for instance, is an example of an independent hospice that now provides both home and inpatient care.

The planning in one community, however, is not necessarily the planning for another, since each community has to determine its own needs, resources, and objectives, either in developing a new service or reforming an existing one. Planning requires limits to be set, priorities established, and plans orchestrated. Whatever form the service takes, relationships must be negotiated and established with other health care services and institutions in the region to assure coordination of effort and continuity of care, since these ideals for care have to be implemented in the real world. An institution aimed at change needs freedom to carry out its ideas, but must also engage in negotiation to secure the approval of regulatory agencies. The urgency of the need to get funds and launch facilities invites compromises and diverts energies from the processes essential in creating an organization that embodies the founders' principles. Thus, communication and a working relationship between the idealists and policy makers are essential to keep the reform viable.

That relationship in the hospice movement is now at a crucial point in the United States, and an inherent problem of all reforms--the adversary position of new ideas versus the existing system--is visible. Reformers and their goals represent changes and thus challenge the status quo. Hospice's emphasis on palliative treatment for the control of symptoms is a challenge to curative treatment of the disease. Intensive personal care for the patient and family is a challenge to intensive technology. Family participation is a challenge to the perception of family as visitors only. Interdisciplinary teams are a challenge to specialization and departmentalization. A system that provides continuous care in a variety of settings is a challenge to multiple health agencies operating separately.

Yet reformers need credibility, funds and formal permission to carry out their aims. Decision making inevitably involves compromise, and everyone involved must ask whether the compromise is necessary and, if so, can the ideal survive. The evolution of the hospice in New Haven illustrates these points.

## IDEALS AND COMPROMISES

Founding St. Christopher's Hospice took twenty years from Dr. Saunder's first recognition of the need to the opening of its doors. Facilities in the United States have taken at the most eight years and as little as one year for planning. The Connecticut Hospice, initially titled Hospice, Inc., had its beginning in 1971 when an interdisciplinary group at Yale University concluded that such a facility was needed. The decision was reached after the group had been involved in a two-year exploratory study that attempted to provide care and other services at home for a small number of patients and families during the course of a terminal illness.[8]

The conclusion was than an independent institution with inpatient beds and home care services was most appropriate for the area and its population, but that ties could be developed with existing institutions in the 19 communities within the area. The number of beds and the capacity of the home care services were calculated on the area's present and future population and its regional planning studies. The incidence of death from cancer in that area now and through the year 2000 was taken into account.[9] Six private foundations shared in the high-risk venture for the first three years with money for planning and for starting home care services.

The first dilemma arose when the hospice sought state approval. The Connecticut Commission on Hospitals and Health Care had just recently been formed, and the hospice's search for a certificate of need was caught in this bureacratic change and the problem of identifying the category of health-related institution into which the proposed hospice could be fitted for ultimate licensing. If it was neither hospital nor nursing home, what was it? What did it resemble most in the public health code and existing reimbursement scheme? Should legislation be sought for a new and separate category? The commission was also concerned with capital and operating costs.

In addition, there was the problem of the physical facility itself. From the beginning, the New Haven group saw physical environment as an essential component of therapy, even though the effects of environment as a therapeutic tool are difficult to assess. It therefore was careful to select an architect who could adapt plans to the patients' lifestyle, allow for family participation, and create an atmosphere where a sense of community could grow within and outside the institution. The design created by Lo-Yi Chain, FAIA, generated excitement among his peers, particularly hospital designers. It reflected the spirit of St. Christopher's but was modified to suit the style of a New England manufacturing and college community with many suburbs.

State officials, however, using customary rules, found it hard to evaluate the plans. A health facility is measured in square feet per patient bed. If family are to be there, more square feet are needed. The hospice notion of four patients to a room (to facilitate communication and relieve isolation) didn't fit the current Connecticut code, which at that time prohibited more than two patients in a room. This dilemma was solved by a state official who proposed that the patients' room be labeled "intensive care units," in which multiple patients were allowed. Intensive personal care was thus equated with intensive technological care.

The case for Hospice, Inc., as it was then known, was presented at public hearings to qualify for that crucial piece of paper, the certificate of need. Ironically, preparing the application and getting ready for the multiple hearings were very costly, requiring lawyers, accountants, and political strategists, but master planning could not proceed until the certificate was obtained. Estimates for capital and operational funds for each year of the first five had to be detailed to the rounding out of one dollar. Education each member of a newly formed commission about the hospice concept took both time and money.

In the prevalent cost-conscious climate, contention centered mostly on capital expenditure. The commission stood firm, so the overall size of the building was cut, amenitites were peeled away, and parts of the building so carefully planned for traditional character and therapeutic effect were jettisoned. That was one kind of compromise.

Further compromise came later, when state and federal governments gave the hospice most of the money for the building, but with the understanding that the facility serve the state rather than the region and that it be a national training center. (This explains why the hospice in New Haven was renamed The Connecticut Hospice.) Can the human scale, the family involvement, the sense of community, and the concern for the patient survive in this expanded institution? Will the caregivers be able to maintain quality of service, as teaching and research responsibilities mount? These questions are yet to be answered.

## A SENSE OF COMMUNITY

As Seymout Sarason has made clear, when societies are creating new organizations, the strains around shaping the new facility are enormous, and building is not only distracting but counterproductive.[10] The physical facilities, however, are only one aspect of the problem of "creating new organizations." There is an interweaving thread of "hospice care"--a community of people who share tasks, resources, and leadership, a sense of total participation, ownership, and collective decision making--that must be preserved. The dying, their famililies, and their caregivers have common bonds which can best be seen in the respect shown to each person's talent. This is hard to sustain over time, but even harder when there are recurrent obstacles to achieving a place in the established health care system. The intensity of involvement, the anxiety provoked by embarking on unfamiliar territory, the need to make difficult decisions without sufficient evidence of balance between right and wrong, and the repeated experience of loss-all these factors create a situation where a strong leader is welcome even at the sacrifice of freedom.

Blending the skills of many professions in a responsibly sharing team, most members of which are accustomed to a traditional hierarchy, requires a different and an additional social adjustment. As Pelligrino has said,

> The whole unexplored territory of mutual obligation, mutual sharing of responsibility and a requirement for a corporate sense of ethical obligations, in which each member of the "team" must feel responsibility for what his colleagues do or fail to do, is put to the test.[11]

When decisions had to be reached in crises, the hospice in New Haven reverted to the kind of decision making from which it was trying to escape, calling upon consultants who understood the existing system. When the board and staff found themselves in unfamiliar territory, they consulted with lawyers, fund raisers, public relation experts, political strategists, and managerial consultants to help with incorporation, legislation, internal organization, third-party reimbursement, licensing, and fund drives. All were eager to guide the neophyte organization through the labyrinth of state and federal regulations and bureaucracies. However, as the circle grew to include all these people as well as family members, volunteers, and, most important, the patient, maintaining a sense of "community" became a delicate balancing act, to say the least.

These consultants, in concert with legal counsel, advised and ultimately brought about changes in the size and composition of the board and in staff organization, a shift in the search for capital and operating funds from the private to the public sector, and a shift in responsibility from the regional area to the state as a whole. Compromises were necessary all along the line, but the Connecticut Hospice is now a functioning reality. Its home care program, begun in 1974, had served 888 patients as of January 1, 1980. The inpatient facility will open within two or three months, but took four more years to complete than originally projected. A separate organization, but with the same executive director - The Hospice Institute for Education, Training and Research - is already giving courses.

It is possible that creating an autonomous institution may require a greater struggle for funding, reimbursement, and credentialing than do hospices associated with large medical centers, unlikely though that may seem. The success of the Palliative Care Unit at the Royal Victoria Hospital in Montreal can perhaps be at least partially attributed to Dr. Balfour Mount's well-established position on the hospital's medical staff and his intimate knowledge of its power structure. Similarly, The Rev. Carleton Sweetser, at St. Luke's Hospice Center in New York, believes that the sense of a total community has survived the technological innovations of that institution and so makes it a good host for hospice care.

Whatever the explanation, however, and whatever the circumstances, those concerned with hospice must be aware that the organizational process and the pressure for speedy action can endanger the democratic quality of the movement. This may be inevitable, given the climate into which a reform movement thrusts itself and the reaction it evokes, but struggle for control in any institution can and does influence the human services it gives.

## OPERATING COSTS

The principle of an open system of care, with patients moving between home, inpatient palliative setting, and inpatient curative setting, is difficult to interpret to cost-regulating agencies. In an open system the true cost of hospice care becomes the total cost during the last period of life, no matter what the setting, and also includes care for the family in bereavement. There is an element of tragedy in the competition between settings over which one can do the work at lowest cost, instead of which can do it best. Issues are seen by bureaucratic agencies in economic terms; proposed care can be easily wrapped in the paper of cost containment to the detriment of its principles.

Yet managers, medical economists, and consultants cannot fix costs and reimbursement until caregivers have determined the quality and quantity of care to be provided. Fortunately, evidence now accumulating appears to demonstrate that costs of hospice care are substantially less than costs for less appropriate care in hospital settings, reaffirming in the United States the experience in England.

There is also good reason to hope that third-party payers will develop reimbursement mechanisms to stimulate hospice programs, although cost accounting present difficulties. For example, there is no precedent for reimbursing services to a patient's family, nor are clergy who help the bereaved after a death recognized as health care providers. Prepaid health plans are beginning to incorporate services for terminally ill patients within their rate structures, but money is hard to get and often entails undesired obligations.

Speaking at the October 1978 meeting of the National Hospice Organization, Neil Hollander of the Blue Cross Association supported the use of hospital beds for a hospice program and also emphasized home care. In his opinion, such an approach would reduce costs. He said that "with empty hospital beds in so many communities, the construction of separate hospice facilities, as in England, may not make good sense." He wants to see hospice programs integrated into the existing health care system and, for inpatient care, he favors the use of existing acute care hospitals and nursing facilities. He suggests that funding should not be available for unlimited periods of time and that inpatient care should be provided on the basis of set criteria.

In recommending use of existing organizational and fiscal structures, however, Hollander did not deal with the elements of hospice care that would be lost, nor did he deal with the limitations of the existing hospital system. This approach leaves unsolved the difficulty of separating the costs for hospice-type care from the patient-day costs in an acute care bed. Former HEW Secretary Joseph Califano, speaking at the same meeting as Mr. Hollander, warned against "mischievous practices which would install a dying patient in a hospital bed in order to justify that bed occupancy as a source of income only."

There is temptation to succumb to the pressures to fill beds, whether or not those beds are staffed properly or are physically adaptable to effective care. Demonstrating the economic advantages of care in the home in contrast to the hospital is currently an influential argument.

## DEVELOPMENTAL FREEDOM OR CONTROL?

The various hospice services springing up over the country have turned to one another to share experiences. The temptation to present a united front against shared obstacles is strong and the need for an information clearing house is obvious. The latter function can be served by the National Hospice Organization, formally organized in 1978.

At first, that organization brought those working in the field together for one- or two-day workshops. Now it has assumed the role of overseeing the development of hospice care within the existing health care system in the United States and Canada. Individuals and institutions involved with hospice programs are invited to become members and to pay dues. At first, voting privileges were accorded only to dues-paying hospice programs that had been given provisional or full accreditation by the organization, but voting privileges have recently been extended to include one regional delegate to be elected by the constituents of each region each year and one state delegate similarly elected. And so the original centralized organization with control in the hands of a few was broadened by its members and made representational.

The organization's stated functions are standard setting, credentialing, gathering, and disseminating information, interceding in legislation, providing technical assistance, training, and evaluation, and the proposed publication of a professional journal. At face value, all these are proper functions of a professional organization. But what will be the effect of such an organization on a reform still in its infancy?

Its members and its members-to-be are faced with a choice between diversity and freedom, on the one hand, and the comfort of central control, on the other. One is reminded of Califano's expressed concern (at the 1978 National Hospice Organization meeting) about the proper role of the federal government and "the dangers of upsetting the delicate mechanisms of individual and free enterprise that now support the hospice movement."

## FOR THE FUTURE

Of the three main forms of hospice organization--autonomous institutions, home care programs, and palliative care units in hospitals--the independent institutions with full home care services are likely to be the most open to innovative practices. In a suitable environment, such institutions can serve as models and also as research and teaching centers. The freedom to experiment and to demonstrate what care for the dying can be in this optimum climate could provide incentives for other programs to incorporate new methods. Sound home care programs remain an essential element of all hospices, including the autonomous ones.

Home care hospice programs with clearly defined relationships to acute care hospitals offer service with a clear focus on strengthening community supports and resources. The opportunity of following the patient when he enters the hospital for specific treatment not only provides continuity of care but also offers the possibility of influencing the hospital's practices by demonstrating involvement with the patient and his family. This affirms the patient's and family's position as members of a community rather than their temporary relationship to a hospital.

Hospice units within hospitals have a capacity, as yet largely untapped, to change the very nature of hospital treatment. The essential humanism of hospice care and the value placed on an interdisciplinary network can only enhance hospital care while offering patients, families, and staff a reciprocal system, one aspect emphasizing cure and the other care. Similarly, the hospice team can promote wider use of hospice methods as the concept becomes legitimized for hospital staff. Home care services are essential here as well and, along with care of the family beyond the time of the patient's death, need to be interwoven with hospital programs.

The ideal of improving the quality of life for the dying is now being put to the test of reality which judges its validity and sense of collective responsibility. As thousands of people propel the movement into buildings and specific programs, can its proponents maintain flexibility and faith in community? Can they allow growth and exercise restraint at the same time? Can they be wise, yet not self-righteous?

The hospice movement is at the threshold of acceptance by government and the medical establishment. Of immediate consequence, therefore, is the way the movement shifts from a peripheral and reform role to integration with the health care system. The task ahead is to maintain values and standards while allowing innovation, accepting regulation, and adapting to existing structures. Most important of all, as we see it, is that the clinical practitioners who have heard and continue to hear the lonely voices of patients and families should remain in the forefront of all new efforts. Their close connection to patients must be the basis for justifying the principles upon which hospice is based.

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# THE MOMENT OF TRUTH: CARE OF THE DYING PERSON

Cicely Saunders

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# THE MOMENT OF TRUTH: CARE OF THE DYING PERSON

Cicely Saunders

The title I have chosen, "The Moment of Truth," includes far more than the question "Who should tell--or should you tell--a patient that his death is near?" I think that the title includes many more of the realities and challenges of the situation. It is a situation that concern all of us, whether we are doctors, nurses, psychiatrists, psychologists, social workers or theologians. (I have deliberately made the list alphabetical, because all are of equal importance.) Perhaps most of all, the situation concerns us when a member of our family or a friend is dying. This is, ro should be, a "moment of truth." It is not a matter of mere words, of who says what; it is a moment with many implications, not only for research and treatment, but implications for the whole of life, and its meaning, implications for us as well as for the patient. But it is the patient who is, or who should be, in the center. The question is his because it is his situation and he is the person who matters. This is why the second part of my title is "Care of the Dying Person" and not simply "Care of the Dying." I think that with the increased interest in this problem there is a danger that the dying may, in a sense, be put in quotes, and I believe it is very important that they should not be. The expression, "moment of truth," was taken by Boros, a philosopher and theologian, for a book about death. But apparently the phrase comes originally from the Spanish, and is a technical term referring to the moment at the end of a bullfight when the matador is alone with the bull. The whole audience, and everybody else in the ring, are secondary. It is just these two together, and the person is absolutely in the center. This is what I want to do now--put the patient in the center. This is why I am going to tell about people I have known in my seven years at St. Joseph's. I am not going to describe my work there very much--I think it will describe itself.

When I arrived at St. Joseph's, I had the good fortune to be given responsibility for some forty or forty-five patients (out of their total capacity of 150) who came with malignant disease, and with a prognosis of three months or less to live. They were sent to us by other centers when the stage of active treatment was over. They were having pain or distress, or had no family to look after them, or had some other complication that made home care impossible. This hospice had a link with the National Health Service and so did the patient, so there was no charge for their stay, and no "parking meter," as it were, ticking away beside the bed. Once a patient came, this was his bed and he could stay. What I must try to do as we proceed is distill the many teaching sessions we have had during these seven years with various groups of students; to try to encourage you, as I encouraged them, just to look at the patients and listen to them to learn from them what they had to teach us. It was far more important that the students should go alone and informally round the wards, and be able to talk to people than to have the usual formal rounds, and then afterwards to sit down over tea discussing the questions that arose. After these informal visits, often they would see the patients in a totally different way, be concerned with the individual people they had been meeting, learn respect and regard for them, and the beginnings of understanding.

Though I do not consider training in psychotherapy a necessity for this kind of work, I do believe that we need all the understanding we can acquire of the patients, who are, after all, people similar to ourselves. Of course, we cannot understand exactly how a dying person feels; death is totally unknown until a person comes to it. But I do think that we can talk of the implications of what individual patients say or do. Moreover, we do not need to have had the same experience as another person in order to enter into it to some extent. We just need to *have had* our own experiences and not to have slid past or, as it were, ducked out from under any hard fact of reality that happens to have hit us. Having had these, we can begin to look at this "moment," which is as much a part of life as any other part, and , for very many, the most important. It is a time of summing-up, a time of final decisions for this person centered, the criterion of success is not how our treatment is working, but how the patient is; what he is doing; or, still more important, what he is *being* in the face of his physical deterioration. Our attitude toward the dying patient betrays a good deal of our attitude toward people in general, and, of course, of our interpretation of the meaning of life. So often, it is *we* who need rehabilitation, not the patient, jsut as it is the psychology of the seeing rather than the psychology of the blind that is the problem.

I speak from a special viewpoint, but, because this is such a very personal part of caring, I do not think it will be too difficult for you to find relevance to your own situations. What I want to discuss concerns attitudes much more than details. I want somehow to convey the sort of atmosphere that I ahve seen as being very helpful to these dying patients--the attention, the security, the hospitality of St. Joseph's. St. Joseph's is a sectarian religious foundation, but welcomes patients of all sorts and kinds, and welcomed me as a staff member of a different denomination. All are wlecomed with a confident sense of strength and peace, with the immense strength of a recognized shared purpose--full-time concern for the patient.

## PROLONGING LIVING AND PROLONGING DYING

I want to talk about the personal achievement of the dying. It is people and the look on their faces that matters, because from the look on their faces we learn both their needs and their achievements. I think we must learn to recognize the moment when our treatment turns into "care of the dying person." To go on pressing for acute, active treatment at a stage when a patient has gone too far and should not be made to return is not good medicine. *There is a difference between prolonging living and what can really only be called prolonging dying*. Because something is possible does not mean that it is necessarily either right or kind to do it. One often sees a great weariness with the sort of pain and illness that brings our patients to us such as that of Sir William Osler who, when he was dying, said "I'm too far across the river now to want to come back and have it all over again." I do not think he would have given a "thank you" to someone who pulled him back at that stage. Recognition of this stage is not defeatism either on the part of the patient or on that of the doctor. Rather it is respect and awareness of the individual person and his dignity. When one patient came to us, she described her situation by saying, "It was all pain." Another patient said to me, "Well, doctor, it began in my back, but now it seems that all of me is wrong." And she went on to describe the physical pain, her feeling that nobody understood how she felt, that the world was against her, that she could have cried for pills and injections but knew that she should not, that her husband and son were having to stay off work to look after her--and that it was wonderful to come to St. Joseph's and begin to feel safe again. She began by talking about her physical problems and her many symptoms but went on to describe mental pain, emotional distress, financial problems, and this need for security. They are all interwoven, tied together, so that you cannot say at one moment that you are treating one problem and not the other. The treatment at St. Joseph's is designed to relieve the pain. Yes, one can do that, to enable the patient not only to die peacefully but to live fully until he dies, living as himself, neither swamped with distress nor smothered by treatments and drugs and the things that we are doing; nor yet enduring in sterile isolation. Now, this is the very opposite of doing nothing, and one can do it.

The patient who had described her world as "all pain" showed a remarkable difference just a few months later when she was relieved and relaxed; when she had given up her flat and organized all her affairs and when she had really forgotten that the medicine she was taking was for pain, because, as she said, "Now it's gone and I'm free," adding, "Doctor, do you think I could leave off the medicine because I really don't much like the taste of gin?" (Our normal pain medication does have gin in it--a good mild sedative.) She did not even remember that it was for that purpose. This was two weeks before her death.

## FAMILY CONSIDERATIONS

If we could, we would want to look after a patient at home. But many patients have so much distress that this is not possible. I have two photographs of a patient, photographs that tell a story. In the first, taken in his ward at St. Joseph's with his wife soon after he arrived, he is sitting up with tense alertness; his face betrays his anxiety, and his wife's face, her despair and guilty feeling of inadequacy. In the second photograph, taken after he had been under our care for a time and was on a diamorphine mixture, he looks as I think a patient ought to look: peaceful and comfortable. He is filling in his football pools (a mild English form of gambling) while his wife sits nearby, her relief at his relief showing in her face. I remember the wife of another patient stopping outside the ward and saying to me, "Oh doctor, I won't hurry in. I'll just stay here and look at him. I haven't seen him look like this for weeks!"

If we can give this kind of comfort to the patient and his family, then we have given them back something in this last time. It is of great importance to both of them. A patient can still be part of his family when he has to be admitted--and he can also fail to be part of his family while he is still at home. Wherever we are looking after these patients we have a tremendous responsibility to help them know they are still part of life and still a part of their own family. We have a photograph of a patient and his wife taken for their golden wedding anniversary only forty-eight hours before he died. Though he did not have the energy to smile, the picture shows his peacefulness and his feeling of closeness to his wife. I recall that when he came to St. Joseph's he was confused and did not recognize his wife or anything else. But after a short while with us he was himself once more. When his wife visited they were as close as they had been at any time during their fifty years of marriage. It is very important to share this "moment of truth" in whatever way one can. It is very important to say "Good-bye." Good-byes matter. We all give importance to saying "Good-bye" when we go on a journey--how much more meaning "Good-bye" has now. We can do a lot to create this sort of quiet togetherness for a couple by telling the patient that we can help him cope with the pain as it comes and letting him know in advance that the moment of death itself is quiet. Then he can, as far as possible, have this moment alone with a relative, shielded from the things that the staff can do something about. You cannot take away parting and its hardness, but you can help it.

Dr. Lawrence Le Shan has spoken of "the wall of glass between the patient and other people." My thought is more of a vacuum around the patient, in part created by the anxious family who keep pulling themselves up and wondering, "Have I let something out?" Then all communication ceases and they are just not able to relax and talk about "something else," let alone real things. This can be a vastly important time, and often family members bitterly regret afterwards that they were not in touch. To get them to talk together, we may first have to do a lot of listening to both sides. We find it easier to do this separately, and we say to the family, who are usually the ones who are concealing their awareness, "You know, he really does realize." We point out that they must not come in being too cheerful and say, "You know, you're going to get better," because the patient is saying, "They won't even let me say "Good-bye" to them." Usually, this sharing of awareness happens quietly, without fuss, and in its own time. I sound as if I take the line of least resistance all the time, but we have found that in our atmosphere at St. Joseph's, this problem resolves itself spontaneously, especially after pain and distress are relieved and we have listened to the anxiety. Sometimes a family member will say, "I can't talk to him. I just can't. I can only keep going without." Then perhaps the patient can talk to us, and then at least he is sharing it with someone. The nuns listen to the families more than I do, for they are always available. They do not have a day off and they are always there, or on call. There is a strong feeling of "Sister's there and I can always talk to her." They often do. But we share together as a group. Conditions in the typical general hospital do not apply in the same way here.

I think it is particularly important to try to help a dying parent say "Good-bye" to the children. I have seen mothers with quite young children saying "Good-bye" not in so many words, but deeply all the same. I have seen mothers doing something special for a daughter. I remember going out to buy a copy of The Messiah for a patient of mine to give her daughter as a last present--a gift which obviously is going to be unusually precious. Sometimes, when patients are failing, they have said to me, "Oh, there's nothing I can do now." You can say to them, "You know, she isn't ever going to forget how you were loving, how you were patient, how you did this, that, or the other while you were so ill."

I know this is true from my own memories, and I have two tape recordings of patients, one in her forties leaving two children who had both been problems, and another separated from her husband, leaving a son about sixteen. They both say the same words, repeating before they died, "I've done what I can." One went on, "I've said what I wanted done, and I have written it all down in my will." The other dictated a letter to me for her children. This was of immense help to them, to feel that they had done all that they could. They could then trust that their children would be cared for, just as they trusted that they would be cared for at St. Joseph's. It is a long way to come, to this place, and as soon as a young patient with a young family comes in, we know that this is going to take special time. We know we are going to feel awed by having to try to help this person face something much harder than anything we ever had to cope with. The fact is that while this is, indeed, sad work, yet when you come to the bedside you are not saying, "How can I help Mrs. So-and-so?" but rather, "This is St. Joseph's and I just happen to be the one here at the moment. And it will be all right."

## COMMUNICATING WITH THE DYING

At St. Joseph's, there is one nun in charge of each ward, but the rest of our nurses are not nuns. Most of them are young Irish girls who come over and do apprentice nursing with us before they go and get further training elsewhere. Since they have not yet been taught to hurry, as many a trained nurse will, they are well suited to work with dying patients. You cannot hurry the dying. You cannot hurry them to realize what is happening; you cannot hurry them to turn over in bed quickly; you cannot hurry them to eat faster than they can manage. Within this slow speed, their own speed, they often make a great deal of improvement. Certainly they are quieter and easier.

I recall being with a patient with a cerebral tumor about two weeks before he died. He had been blind for about six months and was very slow now. His wife tried to get him to look up as I got ready to take their photograph, but he could not manage it and sank back again. She looked up at me and the picture shows the tremendous grace and maturity that I have seen again and again, both in patients and in their families. You might ask, "What is the point of looking after a man for fifteen months since he's going to die at the end?" But there are no short cuts to this kind of maturity. Though there may not be a long time available for a couple to be together, time is a matter of depth and quality rather than length. At this period I remember asking his wife, "Does he always know you?" And she said, "Oh, yes, he does." Then she added, "The other day when I came in I said to him, 'Who's here?' and he said, 'I don't know.' When I said, 'It's me,' he just said, 'Ah, but you're always there!'" It was marvelous how she had gotten across to him the sense that she always was there with him, by her faithfulness, by coming whenever she could, even though she was working at the time. And he, who was a gentle and courteous person by nature, was giving her this absolutely perfect "thanks," and still responding in his own character to the reduced information that his senses were now giving him. He was still much the same person, unique and irreplaceable.

I remember another patient, who, like so many, showed that her heart was still loving though her mind could no longer grasp much at all. A picture of her shows her loving response to an unsophisticated little nurse who is just enjoying her as she is, demonstrating her pleasure in just meeting her, somehow still the same person as ever. Now, this simplicity is a quality we too often lose, but I notice that the young seem to have it almost by nature, if they choose to come into this kind of work. This quality is, I think, important for a relative to observe and feel--to see this person as himself, indefinably the same, still with his own worth until the moment he dies.

## AWARENESS OF DYING AND "TELLING"

Now I have to consider the old question of what to tell the patient. In the first place, I am sure I have to make a distinction between telling somebody his diagnosis (that it is a malignant disease) and his prognosis (that he is not going to get better as far as we can see). I think we have to remember that the degree of insight a patient has into his condition is not under our control. It does not depend just on what we tell him. There are many other factors in the situation--his intelligence, his courage, what is happening in his own body and what this is saying to him, what he overhears. I know that some fifty per cent of my patients not only knew that they were dying but talked about it with me. Of the remaining fifty per cent, there were some who were senile, some who had cerebral tumors, and some who were just not able to have insight. There were others who, I think, recognized but did not choose to talk about it--at least not with me. The choice should be theirs. The real question is not, "What do you tell your patients?" but rather, "What do you let your patients tell you?" Learn to hear what they are saying; what they are not saying; what is hidden underneath; what is going on. Incidentally, only a very few of our patients did know at first that they had been sent to St. Joseph's as the last stage of their journey. Usually they had been told something such as "You need specialized treatment for pain," or "You need longer-term nursing than we can provide in a general ward." Later some of them told me that they had a pretty shrewd idea that it was something like this when they came in. They do not often discuss their diagnosis, which seems often to be irrelevant at this stage, but they do talk about their prognosis, about what is happening, and they all do it differently. Since giving a general description is difficult, all I can do is describe a group of people and tell you what happened to each one of them.

I recall one young woman who had been with us for two months. She and I were quite friendly. I thought she "knew" and that she had chosen never to mention it. She just kept her own counsel until one day she suddenly looked up at me and said with courage and determination in her voice, "Doctor, where did all this begin?" I pulled the curtains round and sat on her bed (as an ex-nurse, rejoicing in the fact that I was no longer bound by the rule that nurses do not sit on beds!). This is important for communicating: standing at the bedside, I would tower over a patient. In this two-way traffic, I want to be on the same level. Then she went on, talking about her family, and soon got to her real question: "Is it wrong for me to let my children come up and visit me now that I'm getting so thin?" She said that she had "known" since her operation six months before, adding, "I haven't talked to my husband about it and I think it would be so hard for him when he realized that I've been carrying this on my own all this time. I just don't know quite how to begin." I told her, "Well, you know, it will just happen, quite easily, and you've been sharing it together anyway." And, of course, having talked to someone else she found herself talking with him the next day. At last it was possible for them to share openly. About a week later she died, but in her face she showed a quietness and acceptance that upheld her whole family.

Other patients are quiet and objective and unworried. I remember one old man saying, quite unexpectedly, "Of course, doctor, I realize this isn't a question of cure now, is it? It's just a matter of jogging along." He was quite sure that it would be all right, that it was his family who needed reassuring. But there are common questions and common fears that lie beyond the one big question that we seem to talk of as if it were the only one. Many are concerned about their families. Many ask, "Will it be very long?" "Will I have pain?" "What will it be like in the end?" Or, "I hope it will be in my sleep." Now, we can be reassuring about it all. If we refuse to discuss it openly, or smother their questions in a kind of blanket of reassurance, they still know very well what is happening. What we have said to them, in effect, is, "I'm afraid to discuss it." They want to talk about the other questions, and they will do it when they are ready if only we will let them. We can also help them without doing so in every word. Effective communication can take place indirectly. Discussing symptoms with a patient, often a way out of having to talk openly, can also be a way to begin. It can give reassurance, understanding, a feeling of "I will be here."

It can be a great release to be frank. I remember one man saying to me, "You know, I've had it all out with my wife and now we can relax and talk about something else." I think that is important too.

Rather unusually, one family took complete control and told a young woman patient so that she could share her knowledge of dying with her husband all the way through. For the two months or so that she was with us, she

she maintained an air of serenity until the end. Of course, this would not work for every family. With another family and another patient the situation is completely different.

I remember one old woman telling me, very firmly, "And when I'm going downhill, doctor, I don't intend you to tell me!" (That reminds me of another patient who, looking at me rather sideways, said, "I know you know how much chance I've got, doctor, but I'm not going to ask you.") Such feelings are to be respected; it is the patient's choice and we should honor it. When the woman was beginning to go downhill I saw her sitting pensively with her great-grandchild on her knee, realizing--but not telling. At St. Joseph's we certainly admit, allow, and welcome children into the ward. They are very important to all our patients, not just the ones they are visiting. The patients need to have this sense of continuity, to know that life is going on. A child, just because it is a child, should be welcomed in this sort of ward.

We all know the very anxious patient who has, as it were, an invisible extra pillow: she can never rest her head right back on her pillow, she is constantly in some kind of tension. Such a person will tend to deny what is happening, will talk only about her symptoms, and has to be reassured by practical things--being given this or that drug or treatment. Not only is every patient different from every other patient, but the same patient will have a different face on a different day. One particular patient made her will with a fair amount of drama one day, and then a week or two later confided to me, "Doctor, you know what I really need is a new set of false teeth." Care of the dying person is a changing situation, and we have to time the help we give to the right moment. Patients will reach out to us on two levels at the same time. And they, too, want a day off! Mankind cannot bear too much reality. There is a day when you think you see a crisis coming and think, "Ah, now we're going to talk about it." Not at all--the patient only wants to talk about the weather, and naturally should be allowed to. The rule is that there are no general rules here except that you must listen. You must be ready to listen; you must be ready to be silent; and you must just be committed.

Sometimes one gets a very direct question. One man asked me a direct question at a stage when I knew him very well and when it would have been an insult not to have fully answered him. Often I give a rather open or perhaps two-way answer and the person can pick up whichever one he really wants. But when this man asked, "Am I going to die?" I just said "Yes." And he said "Long?" and I said "No." He said, "Was it hard for you to tell me that?" "Yes, it was." He just said, "Thank you. It's hard to be told, but it's hard to tell too." His comment was, I think, truly significant. In the first place, it shows how extremely courteous and outward-looking these patients are. And secondly, it should be hard to tell. You just should not be doing this easily. It should be hard because you are trying to bring everything you have of understanding to hear what this patient is really asking you. Then you should be concerned that he does well with what you give him, and that you really are committing yourself to helping him in every way you can, helping him right up to the end. I remember also asking him, "What do you look for most of all in the people who are looking after you?" He thought and said, "Well, for someone to look as if they are trying to understand me. I'm hard to understand." He asks not for success but for somebody who looks as if he cares enough to try. I think that is the fundamental thing. Of course, when you are a student, and when you are a nurse, the patient must know that you really do not know the answer, but this gives you all the more opportunity to try to learn by listening, to ask yourself, "What does the patient really want to know? What is it he's worried about?"

## PAIN

A great deal of my time has been spent with patients who have severe intractable pain. This is really where my interest in this work began. I remember one patient who, when she was admitted, simply could not think of anything but pain. In a tape recording made at the time she said, "I love my family but I couldn't bear to have them in the room because I couldn't think of anything else, and they would have seen the pain in my face." That sort of pain we can control, nearly always without rendering the patient sleepy. Later in her stay at St. Joseph's I looked in on her and found her peacefully writing a letter.

Chronic pain of this kind is a very complicated condition, different from acute pain. One woman had a whole variety of symptoms and problems including a very large, open wound. She was restless and in severe pain. Upon admission the referring doctor had written on her form, "Mainly stuporous now." But that was due to drugs, and not her mental condition. Three months later, she was sitting up in a chair, organizing the ward and so on. When she was finally dying it was she who told me at what stage she thought she really ought to take to bed. I think that to be in such control can be a psychologically healthy and reassuring situation.

I recall a girl newly admitted. When I went in to talk to her she just burst into tears because she expected to be hurt so much the moment anybody came near her. She had chronic pain that went on the whole time but also was exacerbated by movement. The situation held her, as it were, in a vise. As she described it, "The pain was all around me." This is so different from the protective, warning pain of a kitchen burn or of the symptom that brings a patient for diagnosis or the postoperative pain which has a reason and which you know is not going to go on for very long. This is a chronic pain which seems to be timeless and endless as well as meaningless. Now, it is important to realize that many patients make their pain worse by anticipating it. Consequently we should do the anticipating. At St. Joseph's we use our drugs to prevent the pain from ever happening rather than trying to get on top of it once it has occurred. This means a careful analysis of the total situation--the other symptoms, attention to details, a lot of careful nursing, and just listening so that we know what their sensation is like, and so that they know we are interested. I had a patient say to me, "And then I came here and you listened. The pain seemed to go by just talking." She was not just trying to be polite; her perception of pain had really been influenced by our attention and time.

I stopped to talk with a girl about six weeks before she died, and she had the rather "yonderly" look of someone who is beginning to let go. Preparation for dying seems to begin in the subconscious. How much was conscious for her at any stage I do not really know. I had hoped we might get her home again, but when I saw her face that day I knew it would not be possible. The surgeon came up to consult again and told us that nothing more could be done. She had been in our ward for five and a half months, and when she died she was on the same dose of narcotic at which we stabilized her when she first came in. This can be done. The problems of tolerance and dependence can be almost eliminated by the way in which the administration of drugs is managed. It should be part of the whole process of caring for the patient. The aim is that the patient should be alert--alert and himself, and that he should be independent. If every time the patient has a pain he must ask somebody else for something to relieve it, it reminds him that he is dependent on the drug, dependent on another person. But, if instead, the staff can anticipate the occurrence of pain, at St. Joseph's by a system of regular giving of adequate medication to cover the chosen routine time, the patient does not continually have to ask for relief. He can stay alert, thinking of other things, and "forgetting" the pain.

Relief from pain should be given all the way to the end. If it is, the patient can remain himself. I remember talking to one woman who clearly demonstrated the capacity for meeting person-to-person that we so often see in the very ill. This was five days before her death. This woman was Jewish: she was deaf and dumb and she had lived in the east end of London all her life. She could not have had an easy life. But just by looking at her, we knew a great deal about her as she truly was. Our job was to control her distress and pain so that she could be herself until the end.

After this patient died, I remember the woman in the next bed confiding to me, "She didn't suffer. They don't here. I think the motto of this place is 'There shall be no pain.' It makes you feel very safe." This is a safety which gives independence, not dependence.

## BALANCING CLARITY AND REDUCTION OF PAIN

To give enough help up to the end without making a patient sleepy is a problem of delicate balance. If you balance your drugs for the control of incipient confusion, anxiety, and depression the patient will not be sleepy and confused. It is often more difficult to get the balance of the tranquilizers and sedatives than of the analgesics but all the more rewarding for that.

Alcohol remains our best sedative, especially for the elderly. Most of us feel better after a drink; why should the patient be any different? We are allowed to give alcohol in the National Health Service and we are allowed to give gin as part of our favorite pain-relief cocktail, and "it's on the house." Also we encourage relatives to bring in alcohol if they know the patient would enjoy it. I mean quite honestly that a bottle of whiskey may be more valuable than a whole great basket of oranges. A little of what the patient likes does him good. I know you have a problem with alcoholism in the United States as well as with addiction, and perhaps you feel differently, but I have not noticed that Americans feel any differently about serving drinks. I am not suggesting that I have my patients high on alcohol. I am not trying to produce a high positive euphoria. But they come in with a heavy burden, which makes them feel lower than the next person, and we are trying to reduce their burden to manageable proportions. As visitors often remark, our patients look like ordinary, relaxed, serene, cheerful people. I heard one of the students explain the atmosphere this way: "It's the kind of atmosphere that makes one feel that death really isn't anything to be frightened of, but a sort of homecoming." I think she summed it up very well. You just go on. You go on trying something different. You go on listening. You keep coming in, day after day, trying to get the balance right. With some patients you have to keep on trying. With others, you get them balanced and it remains perfect for them to the end.

Personal, caring contact is the most important comfort we can give. It is not necessary always to pay a long visit. Often we are very busy, but there is always time for a brief word. Above all, we must never let the patients down. Never just go by. The dying will lie with their eyes shut just out of tiredness when they are waiting for you. If you then fly past the end of the bed, rather pleased to find them asleep, they have lost that precious moment for which they were waiting. In a Chinese poem of the ninth century A.D. are the lines: "Tranquil talk was better than any medicine. Gradually the feelings came back to my numbed heart." Once a patient knows that you are really interested, he also knows well enough when you are in a hurry. Some of the things to which you listen are not particularly fine, maybe, and some are jolly good grumbles. But I think it is essential that the aggressive person who wants to grumble should be able to do it to you and not to other patients. Somebody who is basically a "doing" sort of person, such as one old patient I remember, a former flyweight boxer, finds it very hard having things done for him. If he is going to let his frustration out and blow some of it off by grumbling away about it, then he should be allowed--not indulged--but allowed to do so.

## THE IMPORTANCE OF CHOICE

If a patient chooses to be out and about, as far as possible we let him. If he says, "Oh, I really must take to bed," we usually find that he is right. He knows what he can manage. On the whole, we really do let him make the choice. I think this is valuable, but it is usually difficult to do in a general ward, where the whole process is geared to getting the patient out, getting him going, and so on. You may see some poor old man propped up in a wheelchair when you know he is just longing, "Please put me back." When a patient does not have much energy, he may want to save it for talking to relatives at visiting time, and not use it being gotten in and out of bed. As far as the control of physical symptoms and the control of pain are concerned, some of our patients say, "I don't want to get used to it." We can always reassure them that what we are using will go on being effective. I find that patients are more often fearful about taking something for sleep than about taking something for pain. I say to my patients, "Now, I'm going to give you something for your restlessness and something for this and something for the other." I do not tell them exactly what the drugs are--they would not remember, anyway. But I do tell them what I am trying to do, and I try to involve them in the situation. I also try to change only one drug at a time, because if you change three drugs and the patient feels sick, which one is responsible? As the guides to public speaking advise, "Tell them what's going on." There is a paper written by a patient who says that he had received many pills and many medicines in his various visits to hospitals and nobody had ever told him what any one of them was for. He said, "I could have at least added one minim of faith if I'd been told in what direction to project my faith."

## THE ISSUE OF EUTHANASIA

I am in the happy position of not being able to carry out drastic life-prolonging measures because we just do not have the facilities at St. Joseph's. Other people have made the decision, at a prior stage, that this is a patient for whom such procedures are not suitable or right or kind. This makes it very much easier for us than for the staff of a busy general ward. I think that it is extremely important that the decision be made by a person who has learned all he can about the family, about the patient himself and about the whole situation. The further we go in having special means at our disposal, the more important it is that we stop and think what we are doing. Of course we must consider the facilities available in the particular institution and the demands on them, but the most crucial consideration is the welfare of the individual patient. In England there is a society that works to get euthanasia legalized. They are specially concerned with the problem of the patients that I work with, those with terminal malignant disease. Though these are not necessarily the most difficult patients to look after, I will stick to them because they are the ones I know best. I have had much correspondence with the former chairman of the Euthanasia Society in Great Britain, and I took him round St. Joseph's after I had been working there some eighteen months. He came away saying, "I didn't know you could do it. If all patients died something like this, we could disband the Society." And he added, "I'd like to come and die in your Home." I do not believe in taking a deliberate step to end a patient's life--but then, I do not get asked. If you relieve a patient's pain and if you can make him feel like a wanted person, which he is, then you are not going to be asked about euthanasia. It is sad that so many patients still do not die in this condition. However, there is no situation in which you cannot get across to a patient that he is a person you care about. Even if you are in a hurry, you can do it; I have seen it happening again and again. This is the positive side of the issue. The idea of euthanasia, legalized killing, is to me morally wrong. But if my own standard of morals, or code of ethics, does not make sense for the other person, I am not going to change his mind by saying that. I think that euthanasia is an admission of defeat, and a totally negative approach. One should be working to see that it is not needed. The great responsibility that we have, those of us who think it is wrong to relieve all pains by euthanasia, is to see that the pains are relieved. After all, this is no more than the total responsibility that you take on with any patient under your care.

## WARD DYNAMICS: DEATH OF A PATIENT

The patient who is upset when another patient dies is usually the one who has just come in, and who does not yet know us or trust us. The patient who has been with us for some time, and knows that the other patient is ready, takes it far more quietly, not carelessly but with a compassionate matter-of-factness which one sees, of course, with the nuns. The nuns have this quality par excellence: this capacity to be matter-of-fact and to go on doing things while showing deep compassion. We do not move our patients away when they are dying. We have one single room on each floor, but we do not move patients into it unless, perhaps, family tradition dictates that ten members of the family sit around the bed for ten days on end or something like that. But apart from such occasional crises the patients remain in their own beds during their final days. This is vital. I have worked in a setting where patients were always moved out, and the other patients were then far more disturbed. You could see them thinking, "What is it like? We never see it. It must be awful." By contrast, when people die in the ward, it isn't "awful." It is always quiet. "It's as quiet as blowing a candle out" is how patients have described it to me. Often it is because they have seen somebody else die quietly that they are finally able to talk about death themselves. They talk not because they have an extra weight of anxiety but because they feel "Oh! Now it seems that it isn't quite so frightening." What counts the most is that they can see that they are not alone. Since we take care that the nuns say the "last prayers" at the last moment, we have to good at knowing when this last moment is. We try hard to see to it that patients are not alone at the end. And so they are in the ward, they do have their cubicle curtains drawn at the last moment, and more often than not Sister is actually there, saying her prayers at the very moment that the patient dies. Often the family is there too. While you may think that this sounds disturbing, it is not. It is aloneness that our patients are most afraid of. It is also essential that we should be good at making the end peaceful. The patient should not be confused, fighting for breath, crying out, and that sort of thing. The end is always quiet and peaceful, and nearly always the patient is in a state of sleep or unconsciousness. The patient who dies fully conscious is rare, but a few do.

Another feature is that one must always let the other patients talk about it, if they want to. We do not force talking upon them, but neither do we say, "She went home in the middle of the night," or "We moved her out into a single room," or some other deception like that. I found out that one old lady was mending her nightdress forty-eight hours before she died because the patient in the bed opposite told me. Then we talked about her. Sometimes patients become extremely fond of each other and they have much to give each other, including emotional support and a great deal of individual helping. But--love costs. It always does. It is hard when somebody you are fond of goes but more than once a patient has said to me, "You know, I gave her her last drink." There is a special communication here.

Sometimes we may have several patients who die, one right after the other. Because we have only about forty-five beds for dying patients out of a wing of seventy-five, the others having long-term illness, we are able to move some around and release the tension. Of course, this is a problem but there are problems in every hospital. My final point on this topic is, we are not afraid of dying ourselves. It is quiet on the ward; there is no sense of panic; it is all right.

## HELPING THE GRIEVING FAMILY

We always tend to feel guilty in bereavement. Indeed, feelings of guilt are part of bereavement. We go back in memory until we find ways that we let the person down. We remember things that we did and now cannot undo. To know that it is natural and ordinary to feel this way can be very helpful. I think that the nurses can do a great deal for the grieving family. The nurse who said to me, "He didn't open his eyes again after you left, you know. You were the last person he saw," helped me more than anybody else. This really did matter to me.

One of the ways we try at St. Joseph's to help the bereaved is just to listen. If a relative wants to say, "Why did God do this to me? Why did He let this happen? Why did the doctor operate?" you must let him do it. You must never stop him. You must never argue. You must let him talk, because expressing these thoughts begins to help toward healing. He may have to express his anguish again and again, but the listener is the person who is needed, and especially the listener who is not a member of the family. The listener from outside can help in a way that another family member cannot. But if we are to learn to help as listeners, we have to learn to accept people as they are. Once when I was complaining about a particularly disturbing and troublesome patient, Sister looked up at me and said simply, "He is himself." People who can allow us to be ourselves are helpful, particularly in bereavement.

One sees that mourning is not just forgetting. It includes a sense of going back to all the ties, and undoing them, and taking out what is really valuable, until in the end what is finally left is no longer grief in the same way, since much has been resolved. This part of the family time together is very important and can make a crucial difference to the whole grieving process.

## THE MEANING OF DYING

A feeling of meaninglessness can be the hardest pain of all for a dying person to bear. Now, you can never impose your own meaning upon another person and his situation, but in a place like St. Joseph's where other people are convinced of the meaning of living and dying, it is easier to find your own way. Sometimes another patient is more help than anybody else. Sometimes the staff have to bear their inability to understand, to feel as if they are not helping at all, yet still go on staying close to the patient. We tend to feel that if we are bringing nothing, then we had better go away. But I think that is just the moment when we have simply got to stay. And if this is the moment when the patient feels that there is no meaning in life and that the weariness of it all is more than he can cope with and we are feeling helpless too, well, we are very much on the same level there. In that place where you share helplessness--there, perhaps, you can help more than you realize.

Yes, doctor, you can show my photograph to anyone you like," I remember a patient saying, "and you can say to them 'It was all right.'" When she had been admitted to St. Joseph's, it was not "all right" for her, but as she found her way it was she who was telling us the meaning, not the other way around. The answer is found by meeting fate, not by demanding "Why?" but by asking "How?" "How do I live in this situation?" It is like Viktor Frankl finding meaning in the life of the concentration camps; like Dag Hammarskjold deciding to say "Yes" to life; learning from Pierre Teilhard de Chardin to accept our own passivities at the deepest level. But for the woman photographed it was not complicated like that at all. The answer for her was just simple, loving obedience to the daily demands of what was going on in a place where she was continually finding help and meaning, finding that love casts out fear.

## THE ROLE OF RELIGION WITH THE DYING

Though there are many similarities among patients who are facing death, each has his unique way of responding. Religion is a real and living thing for a number of our patients, and its meaning grows deeper as death nears. But many of our patients are extremely indifferent to religion, or at least detached from it. I have heard one of the Sisters say kindly of a patient: "His religion's pretty harmless." I doubt that the really aggressive atheist ever reaches us, because the family, knowing that the hospice is run by nuns, would be likely to decide to go somewhere else.

In any case, we certainly never do any imposing. I remember one incident when the Sister reported to me, "You know, I went round the ward the other day and I found Mrs. So-and-so reading the Bible and I said to her, 'My goodness, Mrs. So-and-so!' and she said, 'It's all right, Sister. It's just for the crossword puzzle!'" The fact that we could all enjoy this as a joke is indicative of the atmosphere at St. Joseph's.

Whatever the religious background of our patients, I often see in them something that could be called "reaching out trustfully." They come to remember things from the past, things that they have been too busy to listen to before, and as death approaches, they find that things begin to make sense. They bring a new attention to the old truths. This is something entirely different from plucking at straws, and is an extremely personal matter for each patient.

What I see over and over again with dying persons, and not only because I hope to see this, are the fruits of the spirit--"love, joy, peace, long-suffering, gentleness, goodness, faith, meekness, self-control." For me this is "truth," and this I continually see. The nuns, I think represent Christianity in general rather than Catholicism in particular. What we have in common is much more important than what we disagree about. What I see in patients is to be read of in Martin Buber, the Jewish theologian and philosopher, in Teilhard de Chardin, the Catholic, and in many others--they are talking to each other. I am trying to pin down the intangible. If you have seen it--if you have been with these patients--then you will recognize what I am trying to say.

Patients are often shy to ask for spiritual help; at least, they are in Great Britain. So all the more we have to serve as a link. It is often easier for a patient just to mention it to or to have it mentioned by an ordinary person. Perhaps they can accept this kind of help only from an ordinary person. You have to go quietly and very slowly, but you do need to know, I think, about their need for spiritual help, and classify this term as widely as you like. When professionals talk about the care of the dying, they are often careful to omit this topic completely, or they may say, "Well, it's an individual matter." I believe there is a responsibility on us here; otherwise it is just deciding by default. It is part of total care, even if it is not called by that name, or even recognized. At St. Joseph's I have had the good fortune of working with nuns in an atmosphere where religion is totally integrated into all that we do and think, but never forced on anyone who enters. It is there, largely without words. Florence Nightingale, I think, is the one who said, "You should carry the bedpan for the glory of God." Many would prefer to say, "I'll carry it for the dignity of man." But, you know, the two belong together.

I have been trying to talk, in several ways, about "being present" to these people. Underneath there has been a belief in the person in the midst of life and death and in God as the Truth of the moment of truth. Personal, compassionate trust is really what is behind the atmosphere at St. Joseph's.

In my work one is continually seeing people at their most mature. One could look thus far in this work and say that to recognize this moment of greatest maturity, of the greatest depth of individuality, is a totally satisfying and positive aim and ending. But Eissler, in his book The Psychiatrist and the Dying Patient, talks about the need for the psychotherapist to have some sort of feeling about the immortality of his patient. I would add: perhaps something more than just "some sort of feeling."

I remember watching one man who could concentrate totally on the white hyacinth plant by his bed. I saw in him the relief of that moment of pure pleasure. Somehow it seemed to be saying to him, "The world to which you also belong is good and can be trusted."

I recall the gaiety of that man and of many others. It was not a euphoria induced by drugs and alcohol. It was the gaiety of having gone through doubts and fears and questions and having come right out on the other side. This, I believe, is why one can go on working with these dying patients, day after day, and month after month.

One patient moved from severe anxiety and denial to an emotional stage where one day, when I was sitting on her bed, she suddenly said to me, "You know, doctor, I couldn't ever really imagine myself dying, but there does come a time when you are ready to lay it down." This reminds me of the always uncanny moment when the body, which even in confusion and pain expresses the person, is suddenly empty. To me, the mind and body are absolutely interwoven, but appear to be no more than the tools of the spirit, which is of much more importance. The spirit seems to lay down the body and the mind when death finally comes.

I recall so many who have been truly ready for meeting this "moment." These patients show man's ability to sum up all that he is in this one moment, this moment of truth. In life, we are always looking ahead and never quite getting there. We are always aiming too far, or we are always tipping over into the depths of self-concern. Even so, we bring all that we are into every moment. The "reason why we're here" is a summing up of everything that has happened before. At this stage, and I have seen it again and again, somehow there is a moment that is fully personal and everything is summed up. When Pope John was dying, he said, "My bags are packed and I can go with a tranquil heart at any moment." This is the "moment" of the bullfight--the whole thing summed up.

I remember talking with a patient the day before her death. Her face showed all the quietness and the weariness of dying. Yet she consented to my taking her picture, knowing that I would use it for lectures. She was a warm person who had been in our wards a long time, and she enjoyed meeting students. That afternoon, she was easily able to talk about death and also to ask me to say one or two things to her family for her. Our students used to come round to visit her. She was the sort of person who was helping our work, and she knew it. She could teach far more during just a short visit by sharing her experience, in whatever way she wanted to at the time, than ever I could do in my talking about it. People who are dying often have a tremendous capacity for meeting, or encountering, because they have put aside the mask that we tend to wear in everyday life. Now they are ready to meet, just as themselves, and I am sure this is why you can get to know these patients in an extraordinarily short time, in fact, even in a brief meeting. As students going round the ward said, "She taught us a great deal of wisdom which we will never forget."

The answer to the question of preparation for this kind of work is that you learn the care of the dying from the dying themselves. But only if you look at them with respect and never merely with pity, and allow them to teach you. It is they who show us that the fear of death is overcome. Seeing this, we, too, can come to the place to which I have seen them come so often, and which Ralph Harper describes vividly in his book Nostalgia: "We cannot know what is beyond the end of our days, but we can enter into an order of things which can make us say, 'I'm not afraid.'"

Pearson, Leonard (ed.) Death and Dying: Current Issues in Treatment of the Dying Person. Chapter 3., Saunders, C.M. "Moment of Truth, Care of the Dying Person." pp. 48-78. Press of Case Western Reserve University, 1969. Reprint with Permission.

# MODULE II: COMMUNICATION SKILLS

## PARTICIPANT MANUAL

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# MODULE II: COMMUNICATIONS SKILLS

## PURPOSE AND GOALS

The purpose of Module II is to develop and/or refine the skills of the hospice care nurse in communicating with the hospice patient/family. The goals of the module are to assist the hospice nurse in responding to the psychosocial needs of the dying patient and family through:

- the mastery of basic communication (attending, listening, responding) behaviors
- the mastery of basic instructional methods to teach the family patient care procedures

## MODULE CONTENT

The module content includes the following areas:

- Assumptions and Values
- Attending Behaviors
- Encouraging verbal communication
- Paraphrasing
- Reflection of feeling
- Summarizing
- Self-Disclosure
- Confrontation
- Confrontation
- Problem Solving
- Reassurance and Support
- Teaching functions in hospice
- Applying communication skills to teaching
- Methods of small group instruction
- Adult learning principles
- Design of learning experiences
- Teaching styles

## LEARNING OBJECTIVES

At the conclusion of Module II, participants will be able to:

A. Demonstrate the following seven basic communication skills reviewed in the module.

- Attending behaviors
- Encouraging verbal communication
- Paraphrasing
- Reflection of feeling
- Summarizing
- Self-disclosure
- Support and reassurance

B. Demonstrate knowledge and skills in hospice teaching by:

- Identifying at least three teaching roles in hospice
- Explaining at least two characteristics of teaching roles
- Identifying the three basic stages of group development
- Defining the terms 'contnt' and 'process'
- Identifying the goals of teaching in each phase of group development
- Self-identifying preferred teaching modes
- Designing and delivering a 5-10 minute learning experience

## Module Organization and Overview

Module II has been divided into two major content areas. Section A demonstrates and provides opportunities for participants to practice some of the most essential communication skills inherent in establishing effective relationships with patients and their families. Section B examines the teaching roles of the hospice nurse and provides participants with increased knowledge and skills in teaching patient care procedures to family members.

Communication skills has been placed as the second of nine modules in this curriculum. This early placement within the module sequence reflects the importance of communication skills as a foundation for all of the other knowledge and skill areas in the curriculum. The selection of the key content areas for the module was based on our recognition of the key roles the hospice nurse plays in responding to the psychosocial needs of the dying patient and in supporting and teaching the family to care for the patient at home.

## Submodule A: Basic Communication Skills

This section has been designed to refine the practicing nurse's communication skills in providing care to dying patients and their families. The section begins by examining the role of values and assumptions in the communication process and then focuses on nine specific aspects of the communication process. Our appraoch of breaking the communication process into its component parts is based on a systematic method of teaching counseling that was developed by Allen E. Ivey and Norma B. Gluckstein (1974, 1976). This method is called microcounseling.

On the following pages we will investigate the following nine aspects of communication between the nurse and the patient/family:

- Attending behavior
- Encouraging verbal communication
- Paraphrasing
- Reflection of feeling
- Summarizing
- Self-Disclosure
- Confrontation
- Problem Solving
- Reassurance and Support

For each of these components of the communication process, we will define the specific behaviors involved, outline the goals of each compoenet both from the nurses' and the patient/families' standpoint and provide structured exercises for participants to sharpen their abilities to perform each communication element.

## MODULE II: ASSUMPTIONS AND VALUES

There are a number of barriers that can detract from our ability to communicate with patients and family members. Our own needs, fears, values, beliefs, preferences, and prejudices can shape assumptions about others that prevent effective communication. Each of us, through our personal experience and professional training, has developed certain beliefs, theories and assumptions about the needs of dying patients and their families and the role of the nurse in helping such persons. We also frequently make assumptions about people's needs based on their age, sex, race, ethnic and cultural background, education, economic status, etc. Such assumptions can help or hinder our work depending on how well they help us understand the unique experiences and needs of particular patients/families.

Assumptions often involve attributing feelings and motives to observable behavior. We see a patient crying and we assume first that they are sad and second that they are sad about... A patient or family member talks to us in a short, curt and hostile manner and we assume we have done something (or failed to do something) that was offensive to them. When we act on assumptions, we relate to another as if our guesses about what they are feeling are fact. We often misjudge this other person's experience and thoughts and find outselves saying:

"I'm sorry, I assumed..."
"How silly of me. I thought you wanted..."
"I left because I felt you needed..."

When assumptions are not carefully checked through communication, we may respond to those we are trying to help in a stereotyped manner that fails to meet their particular needs.

Three things to remember about assumptions are:

- Recognize that you will make assumptions about most patients and families with whom you work
- Remain skeptical about your assumptions. See them as theories that need to be tested. We cannot fully know another person's experience no matter how close we are to that person or how similar our experiences have been

- Test your assumptions rather than acting upon them. Using non-judgemental words and phrases, share your assumptions with the person and solicit feedback on the accuracy of the assumptions. Testing your assumptions produces a greater clarity in communication and greater levels of understanding between those involved.

Many of the communication skills we will focus on in Module II will assist you in checking the validity of your assumptions about particular patients and their families.

In addition to our assumptions, there are times that our values may differ significantly from those of a patient or family we are working with. Such divergence in values may pose a significant barrier in helping the patient. Such value conflicts can be reduced by the following.

- Spend time explicitly defining your own values and recognizing particular types of patients you may have difficulty working with.
- Practice expressing your values without trying to convert the person you are speaking with to your viewpoint. You can express your own beliefs and still provide alternative values and beliefs.
- Use team meetings to explore value conflicts and how they are impacting patient care.

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## MODULE II: ATTENDING BEHAVIORS

### Definition of Attending

Attending implies giving attention to, and listening to another. Through attending the nurse demonstrates an interest in, and concern about, what the patient is communicating. The nurse attends to what the patient is communicating, how he/she is saying it, the non-verbal behaviors that are present, and communicates to the patient that these messages are being received and that they are important.

### Goals of Attending

#### Patient/Family Goals

1. To facilitate the expression of ideas, values and feelings by patient/families
2. To establish feelings of importance and self-esteem in patients and families
3. To create feelings of trust, security and attachment
4. To communicate that the patient/family is understood and accepted
5. To allow the patient/family to direct the interaction and assume responsibility for the interaction

#### Nurse Goals

1. To obtain data from the patient/family
2. To focus attention and energies on the patient/family to demonstrate that the nurse is listening and is interested
3. To identify with the patient/family in a holistic manner
4. To validate and evaluate assumptions, assessment and intervention
5. To identify patient/family perceptions

## Components of Attending

Attending is comprised of listening and observing and communicating the fact that you are listening and observing to the patient/family.

In order that attending may be carried out, the nurse must first control extraneous factors to make energy available for attending. Factors such as noise, daydreaming, thinking about what he/she will do next, possible interruptions, the temperature in the room, etc. should all be recognized and, as much as possible, controlled. While attending the nurse is sensitive to what the patient/family is saying, how it is being said and what non-verbal factors are presented which either validate or contradict what is being said verbally. Patients and families very easily identify when nurses are only half-listening.

The first component of attending is listening and observing. The nurse receives information from patients/families in numerous ways. We are interested, here, in the information received through listening and observing. Through listening the nurse hears what is being said and through observing the nurse assesses what the patient is feeling. For example: A patient may say, "I feel fine today" yet be rubbing her leg, frowning and be slumped in bed. There non-verbal cues communicate very different information to the nurse. There frequently is a dichotomy between what the patient says and what the patient feels, Body language, which conveys messages, may be unconscious on the part of the individual and may be extremely important cues for the nurse to assess.

The nurse also demonstrates body language, or non-verbal cues, as to his/her feelings and attitudes. The nurse should be aware of the non-verbal behaviors such as facial expressions, gestures, posture and eye contact that he/she is using.

The second component of attending, communicating to the patient/family that you are listening and observing, is carried out in the following ways.

a. Eye Contact. Nurses should make and maintain, eye contact with the person with whom he/she is attending. In strictly social situations it is considered common courtesy to maintain eye contact with the person to whom you are talking. In attending eye contact is imperative. It should be noted, however, that continuous eye contact may be too threatening to, or uncomfortable for, a patient/family and eye contact may need to be broken periodically for relief of tension.

Eye contact has cultural overtones. In some cultures eye contact may be recognized as a hostile act (amongst some native Americans) and in others it may be thought to be disrespectful (Orientals). Persistent eye contact may be very threatening to adolescents.

b. Posture. Body language is an excellent cue as to what people are feeling. Specific messages are easily conveyed through body positions and gestures.

The way a person sits, where he sits, his position in bed all convey information. It is generally accepted that a person who is seated without slouching, and who leans the upper body toward the person to whom they are speaking, conveys an impression of interest and attention. The nurse should assume a position which appears natural and which is comfortable for him/her. Body position is not static or rigid and changes periodically throughout the interaction.

Social distance between individuals varies culturally. The nurse should develop a sensitivity to patient's spatial territory and not invade this space by sitting too close to the patient/family. Too great a distance, on the other hand, may indicate to the patient/family that the nurse is fearful of coming closer, a detachment from the patient or withdrawal. In so far as possible the nurse should allow the patient/family to determine and set the social distance.

c. Accurate Verbal Following. Through verbal responses the nurse communicates to the patient/family that listening and observations have taken place. The single most important factor is that the nurse accurately responds. The nurse's response must accurately reflect what the patient/family said and what was observed. The nurse should not introduce new topics nor should the patient/family be interrupted. The nurse may indicate that the patient/family is being followed through minimal verbal interjections as "um-huh", "I see", "I understand what your saying", "Oh", "Yes", or by repeating key words that the patient/family have used.

## ATTENDING FEEDBACK FORM

### Instructions:

You will work in triads to practice the attending skills which we have reviewed. The triads will consist of three roles: the sender (representing the patient/family), the receiver (representing the nurse) and an observer who will monitor the attending behavior of the receiver. This form is to be used by the observer to record behaviors of the receiver that indicate listening is or is not taking place.

As observer, you must pay close attention to the nurse's use of attending skills. During the practice session, pay close attention to the interaction between the sender and receiver. At the conclusion of the practice exercise, quickly mark below those behaviors you observed. After completing the form, report your observations to the receiver.

### Behaviors Indicating Effective Attending

_____ Frequent but varied eye contact
_____ Relaxed posture
_____ Leaned forward occasionally
_____ Facial alertness and animation
_____ Encouraging body gestures, e.g., head nod
_____ Brief vocalizations that encouraged continued communication
_____ All comments "on topic"
_____ Warm, interested voice tone
_____ Moderate voice volume
_____ Minimized environmental interruptions

### Behaviors Indicating that Effective Attending is Not Taking Place:

_____ Rigid body posture
_____ Minimal eye contact
_____ Slouching/leaning away from sender
_____ Interrupted sender
_____ Wandered off topic
_____ Distracting gestures, e.g., smoking, playing with pencil, etc.
_____ Talked too much

____ Inappropriate voice volume

____ Fidgeting

____ Stared at sender

____ Abrasive or overdramatic voice tone

## MODULE II: ENCOURAGING VERBAL COMMUNICATION

There are four initial guidelines to encourage patients and family members to verbally express their feelings and thoughts.

1. Demonstrate good listening/attending behaviors
2. Minimize interruptions of patient/family
3. Minimize evaluative responses
4. Keep your responses brief

There are two primary skills which help the nurse facilitate and focus communications with the patient/family. These two skills are the use of open questions and minimal leads. We will examine each of these two skill areas.

### Open Versus Closed Questions

Open questions give the patient room to respond and express their feelings and interests. Closed questions ask for factual information and can be answered with a few words or with a yes or no.

You can usually distinguish open and closed questions by looking at the first few words of the communication. Open questions begin with words such as:

- Could (will) you tell me more about that?
- How do you feel today?
- What would you like to accomplish in the next month?
- Tell me more about that.
- Can you give me an example of that?

Open questions are generally useful in exploring the patient's feelings and interests. Specific situations in which open questions are particularly useful include:

- Beginning an interview. (What would you like to talk about? How have things been going?)
- Getting the patient/family to talk more about something. (Could you tell me more about that? What happened after that?)

- Getting specific examples so the nurse can better understand what the patient is talking about. (Will you give me an example? What do you mean when you say he is hard to get along with?)
- Focusing the patient or family members attention on his/her feelings. (What are you feeling now? How did you feel when she said that?)

Closed questions often begin with words such as:

- Do you feel tired?
- Is your family coming to visit today?
- Are you going back home soon?
- When will they come?
- Where does he live?
- How long have you felt like this?
- How many months ago was that?

Closed questions are not necessarily poor; they are just not likely to produce a lengthy response from the patient. Closed questions are useful.

- When a patient is anxious or not very verbal--they may help the patient get started talking
- When a nurse needs specific information
- When the nurse wants to focus the patient on a particular point
- When the interview is getting too "heavy" and the nurse feels uncomfortable and unable to handle it. Closed questions can help move the interview from deep, emotional material to a more superficial level.

### A Note on Questioning:

1. Avoid asking leading questions that tend to put words in the patient's mouth, e.g., "you do believe in God, don't you?"
2. Avoid "why" questions. "Why" frequently implies scolding, fault finding, impatience, or dissatisfaction. "Why" questions can be turned into "what" or "how" questions and be less threatening to the patient.

3. Many of us overuse questioning in our communications with patients. Many times questions can be turned into statements which leave maximum room for the patient to respond.

   For example:

   "What do you think about...? could be stated as "Tell me what you think about..." or "I'm really interested in hearing about..."

## Minimal Leads

Non-verbal minimal leads include head nods, eye contact, and leaning to the patient to convey your interest.

Verbal minimal leads are brief comments which show the patient that you are listening and encourage him/her to continue talking. For example:

"I see"
"Oh?"
"So?"
"Then?"
"And?"
"Tell me more"
"Um hmmm"
Repeating one or two key words

Such brief responses allow the patient to precede as he/she wishes and lead to greater self-exploration on the part of the patient.

## MODULE II: PARAPHRASING

### Definition of Paraphrasing

Paraphrasing is a verbal response made by the nurse which accurately restates what the patient/family said. Paraphrasing differs from reflection in that the nurse restates only cognitive content of what the patient stated, i.e., the factual aspects. Paraphrasing does not deal with feelings.

When paraphrasing the nurse uses his/her own words to restate what the patient/family has communicated. Fewer words are used than those used by the patient/family.

### Goals of Paraphrasing

1. To communicate to the patient/family that what they have said is understood
2. To allow the patient/family to hear what was said
3. To focus the patient/family in on what was said; to give direction for future communication
4. To validate the nurse's understanding of what has been said
5. To allow the patient/family to correct misunderstandings, expand on what was said or to modify what was said

### Components of Paraphrasing

1. Determining what was communicated
2. Restating what was said

The nurse attends to what the patient/family is relating and filters out extraneous words/sentences to determine the essence of what was said. The nurse then paraphrases what was said by restating it in a concise manner. The nurse must be precise in his/her choice of words so that the restatement is accurate.

### Validating Accuracy of Paraphrase

Periodically the nurse should assess the accuracy of the paraphrase. Through validation the nurse will prevent misunderstanding, prevent interjection of assumptions of the nurse and prevent distortion. The goal is to stimulate a response by the patient/family which will allow the nurse to make a judgement as to the accuracy of the paraphrase. The nurse may use phrases such as "Is that right?" "Did I hear you correctly?" to stimulate a response by the patient/family.

The response made by the patient/family allows the nurse to judge the accuracy of the paraphrase. If the paraphrase was accurate the patient/family will continue, give verbal feedback, such as "right", or non-verbal feedback, such as a head gesture, to indicate accuracy of the paraphrase. During this time the patient/family can modify what was said or decide to change what was said.

## MODULE II: REFLECTION OF FEELING

### Definition of Reflection

Reflection is a verbal statement made by the nurse which accurately states what the patient/family feels. Reflection differs from paraphrase in that it deals with the affective level (feelings and emotions) of the communication. The nurse expresses her perception of what the patient/family feels.

### Goals of Reflection

1. To communicate to the patient/family that feelings are accepted in a non-judgemental manner
2. To allow the patient/family to recognize feelings as a normal part of oneself
3. To permit the statement of feelings which the patient/family may have difficulty verbalizing
4. To validate the nurse's judgement of the patient/family's feelings

Implicit in reflection of feeling is the concept of empathy. Empathy, by definition, means to feel as another feels, to step into his/her shoes and see and feel things from his/her perspective. It is as if the energy fields of another have been entered and the nurse has entered into the patient's frame of reference. In reflection the nurse communicates this feeling to the patient. In order for the nurse to effectively do this he/she must be aware of his/her own feelings and be capable of expressing emotions and feelings. Many patients with whom nurses interact have difficulty in expressing emotion; it is a nursing task to assist patients in expressing feelings and emotions. The nurse must also communicate to the patient that it is permissable and acceptable to express emotions.

### Components of Reflection of Feeling

There are two components of reflection of feeling:

1. Identification
2. Formulation of Response

In identification, the nurse distinguishes his/her own feelings from those being experienced by the patient/family. The nurse assesses patient's feelings through verbal expressions that the patient makes and through non-verbal communication. The nurse then infers, through empathy, what the patient is feeling.

The second component is an active phase: formulation of response. When responding the nurse captures the essence of what the patient is feeling and states this in concise terms to the patient. The nurse can then validate his/her judgement about the patient's feelings based on the patient's response.

Examples of appropriate phrases which nurses might use in a reflection of feeling response are:

It seems that you feel...
Are you saying that you feel...
You seem to feel...
Is it possible that you feel...
I'm picking up that you feel...
You appear to be feeling...
Perhaps you're feeling...
I sense that you feel...

In validating the accuracy of the reflection of feeling the nurse assesses how the patient responds to the statement. The patient may agree with what the nurse has said, or may disagree. This points out the cyclical model of communication and the need for constant reassessment by the nurse. Now the nurse must judge whether the patient is responding accurately or whether the patient indeed feels that way but denies it as he/she can't own up to the feelings.

## REFLECTION OF FEELING FEEDBACK FORM

Instructions: You will be given directions by the instructor for an exercise to allow you to practice your reflection of feeling skills. This form will help you as an observer to assess the reflection of feeling skills of one of your exercise partners.

### Behaviors Indicating Effective Reflection of Feeling

(✓)

______ responded to the primary feelings in the patient statement

______ reflected the feelings at the same level of intensity expressed by the patient

______ varied phrases to reflect feelings; avoided stereotypical responses

______ checked reflection of feeling with patient for accuracy

______ responded to nonverbal expressions of feeling by the patient in a non-judgemental manner

______ used new words to capture the essence of the patient's feelings

______ used fewer words than the patient

## MODULE II: SUMMARIZING

Summarizing is a technique that can be utilized by the nurse to tie together the main points discussed by the patient or family. Summarizing is a verbal condensation of both the feelings and content of a particular discussion topic or it may serve as a review of all topics discussed during one meeting between the nurse and patient/family. In either case, an effective summary should have three basic characteristics:

1. It should be short
2. It should be to the point, and
3. It should not add new meanings or interpretations to what has been discussed.

### Goals of Summarizing

1. To express to the patient/family the nurses efforts to accurately understand what the patient/family is saying and feeling.
2. To verify the nurses perceptions (and assumptions about) the content and feelings displayed by the patient/family.
3. To clarify the patient/family's meaning by pulling together scattered thoughts and feelings.
4. To encourage the patient/family to explore a topic further once the central theme has been identified.
5. To close a discussion topic to clear the way for new topics of discussion.
6. To terminate a session through a concise review of major issues discussed.

### Components of Summarizing

Accurate summarizing has two components: selection and tying together.

The nurse uses his/her judgment to select the key points discussed. As the nurse picks out the highlights of content and feelings, general themes usually begin to emerge. When deciding what material to summarize, the nurse should note consistent and inconsistent patterns that have evolved in the session. For example, the patient may keep coming back to one particular issue, implicitly emphasizing its importance, or the patient may seem to contradict himself/herself by making conflicting statements at different times during the session.

After selecting the principal points discussed or displayed, the nurse attempts to tie together these points and to feed them back to the patient in a more concise way. In drawing together the content and feelings, hte nurse should avoid adding his/her own ideas, which could well be assumptions. The idea is to give back to the patient essentially what he/she has said concisely, using fresh words.

## MODULE II: SELF DISCLOSURE

Self-disclosure is the sharing by the nurse of his/her own feelings, attitudes, opinions and experiences with a patient/family for the benefit of the patient/family. Self-disclosure can include the nurse communicating feelings he/she experiences in talking with the patient/family ("I feel very sad when you say that.") Self-disclosure can also involve revealing the experiences and feelings the nurse has had in the past to help the patient/family achieve greater understanding of their current situation.

### Guidelines for Self-Disclosure

Self-disclosure can have strong and at times unintended effects on the nurse-patient/family relationship. The following guidelines are intended to provide knowledge on the needed timing and content of self-disclosure by the nurse.

1. The nurse's disclosure should relate directly to the patient/family's situation. Disclosure should come only after the nurse has used other interventions e. g. paraphrasing reflection of feeling, etc. to make sure that they clearly understand the patient/family's situation. A key check on the timing and content of self-disclosure is to ask oneself, "Am I wanting to reveal this for the patient/families needs or for my own needs?"
2. The disclosure should be relatively short and directly to the point. Communicating lengthy stories and experiences tends to shift the focus of the session from the patient/family to the nurse.
3. The nurse should reveal information about themselves only on a level of intimacy they are comfortable with. Ask yourself: "How will I feel later about having disclosed these feelings and experiences to the patient/family? How might such revelations effect my feelings toward the patient/family?"

## Problems of Self-Disclosure

There are some problems sometimes associated with self-disclosure of which the nurse should be aware.

1. Self-disclosure, by touching sensitive areas of the nurse's life, can break the empathic contact between the nurse and the patient and, as noted earlier, shift the focus of the session from the patient to the nurse. Some nurses may find it difficult following self-dislosure to bring the point of self-disclosure back to the experience of the patient.
2. The premature use of an intimate past experience or a threatening present feeling could make the patient anxious and could damage the relationship.
3. There is a certain amount of risk to the relationship any time the nurse uses self-disclosure.

## MODULE II: CONFRONTATION

### Definition of Confrontation

Confrontation is the deliberate interaction by the nurse to stimulate the patient to explore something that the patient is uncomfortable about or is avoiding. One assesses the need for confrontation through identifying discrepancies or contradictions in patient's statements and behavior. It can be viewed as an unmasking of the patient's distortions. The nurse assesses information given by the patient and the patient's feelings and puts it together in a way that the patient has not been able to do. Confrontation is an extension of empathy and is dependent upon empathy having taken place. Confrontation is not an attack, negative or punitive.

### Goals of Confrontation

1. To assist the patient in exploring things that are painful and conflictual
2. To identify areas of inconsistencies, discrepancies and conflict
3. To help the patient to recognize defense mechanisms that are being used
4. To assist patient in analyzing their (own) behavior and feeling and to accept responsibility for them
5. To demonstrate concern by the nurse for the patient

### Types of Discrepancies/Distortions

Patients (individuals) contradict or distort when reality does not match desires. Descrepancies occur between:

1. What we feel and how we behave
2. What we say and what we do
3. How we view ourselves and how others view us
4. What/who we are and what/who we wish to be
5. What is said at one (particular) time and another

6. How one reacts and how (others) most people would react in the same situation

Distortions in behavior occur when one can not face things as they are in reality. One then changes behavior in attempt to create balance.

Guidelines for Effective Confrontation

1. Do not accuse, attack or punish
2. Use confrontation only when trust and empathy have been established between you and the patient/family
3. Confront specific, concrete behaviors which the patient will be able to change
4. Utilize patient's strengths when confronting

## MODULE II: PROBLEM SOLVING

### Problem Solving Outline

Step 1: Involve the Patient and the Family

Step 2: Define a workable Problem

A workable problem has two characteristics:

a. a specific statement of the problem--the situation as it is now--that is narrowed down enough to address

b. the direction of change that is desired. You and the patient/family must come to some understanding about the desired change

If there are a number of problems to be addressed, prioritize the problems as to their importance and the ease with which they can be resolved. It is usually best to begin with problems that can be more easily solved.

Step 3: Analyze the Problem

Conduct a force field analysis by listing factors working for and against change of the problem.

| FORCES FOR CHANGE | FORCES AGAINST CHANGE |
|---|---|
| 1. | 1. |
| 2. | 2. |
| 3. | 3. |
| 4. | 4. |

Step 4: Explore Alternatives

There are usually two ways to solve problems:

a. making a force for change stronger

b. making a force against change weaker

Step 5: Gather Information on Alternatives

Step 6: Re-examine goal and alternative choices

Step 7: Develop and implement an action plan

Step 8: Feedback and follow-up

## FORCE FIELD WORKSHEET

Instructions:

Select a patient/family or personal problem that you have recently experienced. After reflecting on the desired nature of change, complete the following force field analysis

| FORCES FOR CHANGE | FORCES AGAINST CHANGE |
|---|---|
| | |

What alternatives would (or did) you implement to increase the forces for change or reduce the forces against change. ______________________

______________________________________________________

______________________________________________________

______________________________________________________

## MODULE II: SUPPORT AND REASSURANCE

(Refer to attached article by Enelow and Adler)

In previous skill areas the nurse has assumed a relatively passive role allowing the patient to direct the communication. In working with hospice patients/families nurses may find it necessary to take a more active role in order to give support and reassurance.

### Goals of Support and Reassurance

1. To demonstrate acceptance and understanding of patients and their families
2. To focus patients/families energies and behaviors in a particular manner

It should be remembered that to the patient and family the nurse represents an authority figure. Therefore, whenever the nurse utilizes a degree of control he/she represents a certain degree of authority. Thus, an atmosphere of trust and empathy should be established prior to the use of control. As a first condition the nurse should unconditionally accept the patient and family. The patient/family should be allowed to express feelings and attitudes without judgement by the nurse. They should be allowed to make mistakes without experiencing rejection. Experiences should be viewed from the patient's/family's perspective and the nurse should be extremely sensitive to the use of the words "you" versus "we". The patient/family should be allowed to set the standards or norms.

### Support

The nurse demonstrates support through words or behavior to indicate interest, acceptance and understanding. The purpose is to promote feelings of understanding. The nurse should be sensitive to the words that are used and also non-verbal cues which communicate the nurse's attitude. Silence is an important factor. For instance, the nurse does not have to respond verbally to demonstrate support; staying with the patient and not leaving him alone may be more important than any words in communicating support.

### Direction

Direction is a relatively high form of control; it in some way lets the patient know what should be done. Relating to verbal direction an example might be a nurse saying "Tell me more about that" or "Tell me what you are feeling". If a lesser degree of control is desired the nurse could say: "Could you tell me more about that?" This gives direction to the patient but permits some degree of control by the patient.

### Suggestion

Suggestion reflects a lesser degree of control than direction. It is used to guide the patient's/Family's thinking and behavior. If when a nurse administers a pain medication she says, "This should help in a few minutes", she has suggested to the patient that the probability of relief of pain is high.

### Reassurance

Reassurance should always reflect reality. For this reason statements which are so helpful in other situations are not appropriate in hospice. For example, it would be rare that the nurse could reassure the family that "everything will be fine." Reassurance should be demonstrated to the patient/ family by using words/behaviors that restore or maintain their sense of self-esteem. For example the nurse might say, "I can understand why you feel that way".

### Submodule B: Applying Communication Skills to Hospice Teaching Functions

The exhibits on the following pages will be utilized to illustrate the lecture and exercises on the use of teaching skills in the hospice setting.

## EXHIBIT A

## TEACHING SKILLS/FUNCTIONS IN HOSPICE

| FUNCTIONS<br>SKILLS | Patient/ Family: Hospice care | Patient/ Family Death, Dying & Grief | Patient/ Family: Care Techniques | Patient/ Family: Communication Skills | Staff/Nurses: Hospice, care & Communication | Interdisciplinary Team-Patient family statue & communication | Community hospice |
|---|---|---|---|---|---|---|---|
| Briefing | ● |  |  |  | ● | ● | ● |
| Instruction | ● | ● | ● | ● | ● |  | ● |
| Facilitation | ● | ● |  | ● |  | ● |  |
| Monitoring |  |  |  | ● |  | ● |  |
| Modeling | ● | ● | ● | ● | ● | ● | ● |
| Team-Building |  | ● | ● |  |  | ● |  |
| Feedback |  | ● | ● | ● | ● | ● |  |

## EXHIBIT B

## DEFINITIONS OF TEACHING SKILL AREAS

### Briefing

Organizing and distilling alrge amounts of data and information for for quick presentation and comprehension.

### Instruction

Desinging and conducting a learning experience for a specific purpose.

### Facilitation

Ensuring discussive participation and interchange on a specific idea/issue/problem by members of a group.

### Monitoring

Observing individual or group activity/performance and providing content or process interventions as needed.

### Modeling

Demonstrating the behaviors, skill applications and attitudes being transmitted or taught to others.

### Team Building

Defining roles and interactions among group members in consideration of group and task needs.

### Feedback

Delivering specific observations about behaviors and their effects upon others

## EXHIBIT C

## TEACHING INTERVENTIONS IN THE THREE STAGES OF GROUP DEVELOPMENT

| STAGE | CHARACTERISTICS | NEED | TEACHING SKILLS |
|---|---|---|---|
| 1 | Dependence (infancy) | orientation<br>information<br>expectations<br>setting | briefing<br>instruction<br>modeling |
| 2 | Testing (adolescence) | questions/<br>answers<br>disclosure<br>skill development<br>practice | instruction<br>facilitation<br>feedback<br><br>modeling |
| 3 | Conjoint Functioning (maturity) | autonomy<br>problem solving | monitoring<br>feedback<br>modeling |

## EXHIBIT D

## CHANGES IN CONTROL ROLES

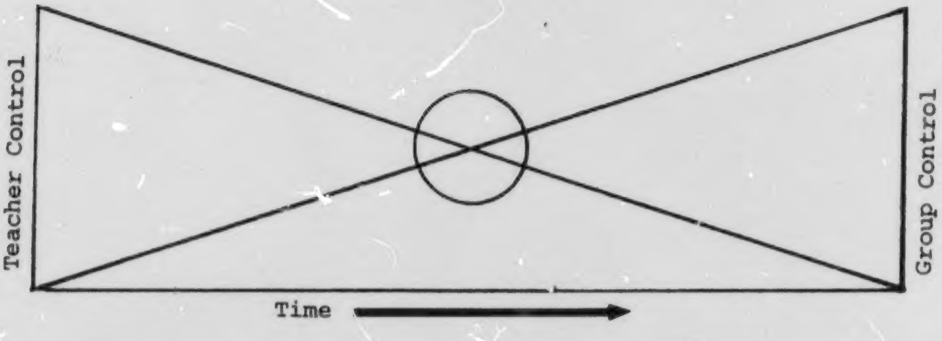

EXHIBIT E

## STRUCTURED LEARNING EXPERIENCE OUTLINE

| LEARNING GROUP CHARACTERISTICS | LEARNING OBJECTIVES | METHODS | EVALUATION |
|---|---|---|---|
| Stage | What should they learn? | Given the group and the learning objective, how should the learning take place? | What seemed to work? Why? |
| Needs | | | |
| Motivation | How well do they need to do it? | | What didn't? Why? |
| Others | | - environment<br>- role<br>- practice<br>- time | What needs to be changed? |
| Cultural Language | | | |
| Environment | | | |

## EXHIBIT F

## STRUCTURED LEARNING EXPERIENCE WORKSHEET

| LEARNING GROUP CHARACTERISTICS | LEARNING OBJECTIVES | METHODS | EVALUATION |
|---|---|---|---|

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# BASIC INTERVIEWING

Allen J. Enelow, M.D.
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# BASIC INTERVIEWING

Allen J. Enelow, M.D., and Leta McKinney Adler, Ph.D.

## 1. THE CLINICIAN-PATIENT RELATIONSHIP

What we would term an effective clinician-patient relationship is ideally characterized by trust and confidence in the clinician; a feeling of relative autonomy and appropriate participation on the part of the patient; continuity of the relationship with flexibility in its nature and depth; and reasonable expectations on the part of both doctor and patient.

### Trust and Confidence

Illnesses that cause people to seek help are very often accompanied by anxiety, a feeling of helplessness, and disturbances of the relationships between the patient and others around him. Often, too, illness leads to a disruption of family functioning and to loss or threatened loss of income. Therefore, the patient comes to the physician with a characteristic mixture of hope and fear. He hopes that the physician will be able to discover the cause of his discomfort and take appropriate steps to set things right. At the same time, he fears that the physician may not be able to help him and, in some instances, that help is not possible. These fears may be compounded by apprehension over the cost of care, or the possibility of painful, disabling, or disfiguring treatment procedures.

Initial trust in the physician's professional skill is usually created by the degree of confidence the physician communicates by his manner and by such things as diplomas, certificates, and office atmosphere. It is another thing, however, to have a feeling of personal trust and confidence in the physician. Trust and confidence are built when the physician provides support and when he respects the patient's autonomy. They are also created when the physician (or other clinican) maintains the reserve that defines him as a professional person whose aim is to help, and who seeks no reward from the relationship beyond those given to the professional person for being successful in his work. Of course, previous successful treatment of the patient or his family or friends also provides a basis for trust.

### Autonomy and Participation

Three types of doctor-patient relationship have been described by Szasz and Hollender: activity-passivity, guidance-cooperation, and mutual participation.[1] The major variables in the three relationships are the degree of participation and feeling of autonomy on the part of the patient.

In the activity-passivity relationship, the physician uses all of the authority inherent in his status, and the patient feels no autonomy, tries hard to please the physician, and does not actively participate in his treatment. While usually required in the management of emergencies, it is the poorest type of relationship for diagnostic interviewing and data-gathering, as well as for much treatment.

In the guidance-cooperation type of doctor-patient relationship, the physician still exercises much authority and the patient is obedient, but the patient has a greater feeling of autonomy and participates somewhat more actively in the relationship. This is more appropriate than the activity-passivity model for a diagnostic interview. But a guidance-cooperation relationship does not encourage emergence of the widest possible range of relevant information. The desire to please the physician still may cause the patient to restrict information to what he perceives is wanted, as well as to bias the information he gives in a direction that seems to be desired by the interviewer. Alertness and great skill in phrasing questions on the part of the interviewer are necessary in order to overcome this tendency. Later in the interview, during the detailed inquiry commonly called the review of systems, a guidance-cooperation relationship is appropriate.

The mutual participation relationship is the most desirable for the diagnostic interview, as it is for the management of chronic illness. Here the patient feels some responsibility for a successful outcome, which involves both active participation and a feeling of relatively great personal autonomy, that is to say, responsibility for his own behavior. This is created by appropriate moderation of the physician's use of his authority, a theme that will recur throughout this chapter. In such a relationship, the widest range of relevant diagnostic information tends to emerge and the most successful outcome of treatment is likely to occur. While it is true that some dependence on the physician is useful, especially in acute and frightening illness, it is generally not useful to foster the patient's feeling of dependence. Dependence can reach a point where it interferes with treatment and prolongs the relationship. The best clinician-patient relationships encourage the patient to take increasing responsibility for himself, at a time and rate consistent with good treatment.

### Continuity and Flexibility

While the clinician-patient relationship ideally has continuity, it is characteristically flexible in both nature and depth. There are times when the relationship is intense and involves frequent contacts and detailed explorations of the patient's physical and personal life. At other times, the relationship is casual and occasional, perhaps consisting of an annual checkup or help for a minor and limited disorder, such as a simple laceration or sprain. The nature of the relationship may vary from the careful exploration of unexplained severe and acute symptoms to counseling, and from routine procedures such as inoculations or superficial physical examinations to intensely emotional encounters during times of stress or crisis in the patient's life. In the most successful clinician-patient relationships a data bank is built through repeated encounters. New information is added as each new problem is explored and its solution sought. The ability to establish this kind of relationship is primarily a function of the emotional and supportive aspects of the interview.

### Reasonable Expectations

The patient's expectations from the doctor-patient relationship, and therefore from the interview, are very much influenced by the pain and fear he is experiencing when he consults the doctor. The patient expects to have the source of his disorder found and corrected. He also expects some degree of comforting or care from the physician and some reassurance. His view of a successful outcome of his treatment is that it produce a positive feeling of well-being, not just the absence of pain or discomfort. The fact that this outcome is not always possible is never easily accepted by patients, except for those who are "professional patients," that is, those who have learned to obtain gratification from the sick role. It is important that the physician deal realistically with the patient's expressed and unexpressed expectations from him and from their relationship. Open and frank discussions about prognosis are usually helpful; tact and an understanding of appropriate timing are necessary.

## 2. THE INTERVIEW MODEL

What kind of interview is most likely to produce a relationship characterized by trust and confidence, and appropriate degree of autonomy and participation, flexibility in its nature and depth, and reasonable expectations on the part of the patient? It is our view that an open-ended interviewing style is most likely to produce the desired type of clinical relationship and to be both effective and efficient in the task of data collection.

Before describing this open-ended model, let us examine two alternative approaches to interviewing. Our observations of physicians in postgraduate courses and of house officers in university hospital clinics led us to conclude that the average medical interviewer is likely to seek information in the most direct manner possible--by asking a great many questions. This style of interviewing might be called directive-interrogative. It is often referred to as history-taking. The physician has a long "list" of items in mind about which he wishes to have information. Each bit of information given him by the patient is followed by several specific questions elucidating details. In a number of observed situations, certain consistent effects of this interview sytle were noted. The patient has a tendency to become quite passive. Often the patient makes some early efforts to bring in personal concerns, then ceases the efforts and limits his communication to supplying the information that is being sought. When the interviewer and the patient come from different cultures or different social classes, the patient may struggle to understand the interviewer with limited success. The interviewer often responds with increasingly specific questions (and sometimes with irritability). The relationship has rarely deepended by the conclusion of the interview. Important diagnostic clues, particularly in the psychological and social areas, may not be picked up.

In the mental health care disciplines, by contrast, one is likely to find very little emphasis on fact-finding through an inquisitory technique and a much greater emphasis on the development of rapport. Much attention is paid to the empathic responses of the interviewer and to the facilitation of communication, and correspondingly less attention to data collection. Facts are not actively sought; they are permitted to emerge. This is especially true of the psychiatric interview that will lead to psychotherapy and of the social worker's casework interview.[2]

The open-ended interview to be described here is a derivative of the interview styles that have emerged in the mental health professions. It has been modified to fit the medical or health care setting. It combines the goals of the fact-finding type of interview with the concern for rapport and the emphasis on emergence of information, rather than the extraction of facts, that characterize the interviewing style of most mental health professionals. The description of the characteristics of the open-ended interview and the most likely responses of patients to the interview behaviors of the physician are based on five years of research in interviewing, using an interaction analysis scale developed by Adler and Enelow.[3,4,5] The guiding principle of the open-ended interview is that the clinician should exert the least amount of authority necessary to obtain the information he is seeking within the time allotted for the interview.

There are four general characteristics of this style of interviewing. First, the interview should be carried out in an atmosphere that encourages spontaneous behavior on the part of the patient. Second, the interviewer's behavior should encourage communication. Third, the interviewer should give attention to the patient's non-verbal behavior as well as his story. Fourth, the interviewer's specific information-seeking actions should be those that exercise the least control first, and the highest degree of control as late in the interview as possible.[6]

### The Atmosphere of the Interview

An atmosphere that encourages spontaneous behavior has both physical and emotional attributes. Comfort and privacy should be provided whenever possible. The interviewer should arrange for the fewest possible interruptions.

### The interviewer's behavior should encourage communication.

The interviewer should communicate by his manner that the patient can respond freely and discuss whatever he wishes. As a rule of thumb, the fewer the clinician's utterances to keep the patient talking, the better. This is especially true in the earlier part of the interview.

### The interviewer should give attention to the patient's non-verbal behavior as well as his story.

Non-verbal communication is often more indicative of a patient's inner state than his verbal account. Information not contained in words may be clearly expressed in behavior, manner, and appearance. An important way of facilitating the patient's spontaneous account is to call his attention to the observed behavior.

The interviewer should move through a cycle of information-seeking behavior that begins with low use of authority and proceeds to progressively greater use of authority.

The interview is best opened with a broad open-ended question such as "What kind of difficulties are you having?" As the patient answers, the interviewer should encourage spontaneous elaboration on his account through facilitating remarks and gestures. If the interviewer observes that the patient is encountering difficulty in describing his problems or discomfort, or finds it difficult to understand his account, he should point it out to the patient. If there is incongruity between the patient's behavior and his account, the patient's attention should be drawn to the observed behavior. Lastly, if these methods have not yielded specific items of needed information, or at that point in the interview where specific details are needed to fill in the story, the interviewer should use direct questions.

The principle is this: spontaneous reporting tends to produce the broadest range of information, most of which is likely to be relevant. When verbal communication ceases, non-verbal communication continues. Pointing out the non-verbal behavior tends to encourage the verbal expression of the inner experience. For example, a patient who is told that he has a worried and pained look may then describe his chronic low-grade neck stiffness and headache. Feelings, such as sadness or fear, may be first expressed after the non-verbal (behavioral) evidence has been brought to his attention. If this does not succeed, questioning may be necessary. If the patient can express himself well, very few questions may be necessary. A very important reason for limiting the interviewer's control over the patient's communication is to minimize bias in the information offered. The wording, timing, and sequence of questions, as well as non-verbal behavior accompanying them, all may provide cues that influence the patient's replies.

## 3. BASIC INTERVIEW TECHNIQUES

### Opening the Interview

The open-ended question, such as "What kind of troubles have you been having?" says to the patient, "I am interested in anything you may feel is important enough to you to tell me." In return interviews, an appropriate variant might be, "How have you been getting along?" Interviewers who do not use the open-ended question frequently close off whole veins of important information since they do not give the patient permission to develop areas not covered by the interviewer. Yet some patients, especially children and adolescents but also adults, are unable to respond to an open-ended question with a detailed account. In such a case the interviewer may be tempted to begin direct questioning at once. If the sole reply to "What kind of troubles have you been having?" is "Well, I've been having a lot of headaches," followed by silence, the clinician may fall into the trap of asking a series of questions like "How long have you had them?", "How long do they last?", "Where does the pain seem to be?", "What relieves them?", and so on. Each specific question the doctor asks will increase the probability that the patient will give the exact information requested and lapse into silence awaiting the next question.

Before embarking on a line of direct specific questioning the interviewer should try less controlling actions. These are silence, facilitation, and, if appropriate, confrontation.

### Silence

The least controlling thing an interviewer can do is to be silent and "give the patient the floor." If the patient falls silent, the interviewer should consider being silent himself for at least a brief time. Ordinarily the patient will soon feel free to resume his account. That the clinician is not speaking does not mean that he is not communicating. His facial expression, posture, and movements all tell the patient something about the interviewer's response to his account and to him as a person. An attentive facial expression and posture tell the patient non-verbally that he has an interested listener. On the other hand, standing over a bed patient suggests that you will not remain long enough for him to tell you very much. It is a good idea to look at the patient but not stare continuously into the patient's eyes. Looking distracted, fidgeting, slumping in an attitude of fatigue, looking away from the patient, and examining the chart all indicate that the interviewer's attention is not fully focused on the patient. This non-verbal message will inhibit the patient considerably.

Thus while the patient is communicating freely about important matters, the doctor's behavior of choice is an interested, attentive, and relaxed silence. Whether to remain silent or to speak when the patient falls silent is a choice which requires the skill that comes with experience. During an interview silences of only a few seconds often seem interminably long. Silence is frequently quite uncomfortable for the inexperienced interviewer. The busy practitioner is also likely to tolerate silences poorly because of his schedule consciousness. A common response of both beginner and busy practitioner is to search for a question or a remark to keep the conversation going. But one can learn to tolerate silences through practice. This is a worthwhile exercise as there are times when it is very useful to the interview for the clinician to maintain his silence after the patient has stopped speaking.

One of these times is when the patient has stopped speaking in order to clarify his thoughts, to recollect facts, or to find a way of adequately expressing something. The patient may explain such silences with remarks like, "Let me think a minute," or "How can I say that better?" This kind of thoughtful silence is rarely accompanied by signs of increased tension. The perceptive interviewer can usually recognize this situation and wait for the patient to continue. An interruption may make it more difficult for the patient to express himself clearly.

Another situation requiring a decision whether to remain silent or to initiate some action occurs when the patient appears to have said all he wants to say and has come to a natural pause. The pause may be signaled by a remark and by the patient's demeanor indicating that he has finished and is waiting to hear from you. The best choice at this juncture depends on a number of circumstances.

First, the clinician should consider how often these pauses have been occurring and how lengthy and complete the patient's narrative has been. If the patient has been limiting his remarks to a few phrases or sentences, then waiting for you to take the initiative again, you may have been interrogating him. If you have been asking a great many direct questions, continuing after brief replies, the patient will assume that brief replies in response to your questions are what you wish and expect. If, upon reflection, you feel you have placed yourself in such a situation, a pause on your part may encourage the patient to go on. If the patient continues to remain silent, it may be helpful to try a comment or facilitation with a relatively low level of control.

If, after reflecting on the course of the interview, you realize that you have been working hard to help the patient tell his story on his own, and you sense that the patient is "holding back" and that his non-verbal behavior reflects tension or discomfort, your silence is again likely to be appropriate: in the silence which follows, the patient's discomfort may well increase, and he may then tell you on his own what is bothering him and give you an opportunity to deal with it. This could be something in the immediate environment, such as telephone interruptions, the intrusion of office personnel, or a feeling that you are uninterested. On the other hand, it may be reticence, shame, or embarrassment about telling important parts of his story. The difficulty in communication which has developed may also be due to the patient's discomfort in speaking freely to someone of different sex, age, class, race, or ethnic background. The patient may fear the possible diagnosis and react to this anxiety by failing to communicate freely in order to "ward off" the knowledge that he has the disease he dreads. Or his discomfort may be related to important events or circumstances in his personal life that you need to know about in order to manage the patient's treatment successfully. Whatever the reason for his evasiveness and discomfort, a pause will allow his discomfort to become clearly evident to both of you. If he does not speak about it spontaneously, you are ready to point out the difficulties in communicating which you have been observing. A confrontation in this situation will frequently result in a discussion of the difficulty the patient is encountering. This will usually permit the interview to proceed smoothly.

The situation in which a patient has been communicating freely but shows increasing difficulty with a particular topic and halts the account is another instance of silence best handled by remaining silent. In the ensuing pause, the emotional basis for the failure of communication may become apparent, and the clinician can then proceed with a confrontation leading to a discussion of the difficulty.

There is one time when it is mandatory for the clinician to remain silent. This is when the patient has stopped speaking because he is overwhelmed, or about to be overwhelmed, by emotion. Sometimes one may forestall or attenuate an expression of strong emotion, most frequently weeping, by prematurely saying something to the patient, thereby failing to reduce the patient's tension. There are several reasons for remaining silent until the patient has expressed stong emotion and brought his feelings under control. Foremost is that open expression of feelings is almost always therapeutic for a patient. In addition, it is likely that a patient will be able to express himself more adequately after a release of emotion. He may well be able to speak of things which he could not bring himself to discuss before. If, on the other hand, the patient decides to control himself and withhold his feelings, he has the opportunity to do so. He makes the choice himself; it is not forced on him.

The extent to which the patient is helped and the interview is facilitated by permitting a display of feeling depends very much on what the doctor says and does after it has subsided. A supportive response is almost always helpful. This will be taken up in a later part of this chapter.

In some cases it will not be appropriate for you to remain silent when a patient pauses. If an overly talkative patient who has been dominating the interview and preventing the efficient gathering of diagnostic information stops talking, for example, you might take the opportunity to obtain some of the information you need. Another time that you would not necessarily remain silent at the patient's pause would be when you felt a need for clarification of what the patient had been saying. There are several ways you might choose to proceed and they will be described later.

In the early part of an interview, silence may allow the patient to go on to a new topic. If the patient shows signs of increasing tension as a silence develops, one can acknowledge what was just said, ask a broad question concerning this or other problems the patient may have, or comment on the patient's discomfort. Near the close of the interview, when the interviewer feels he has a generally complete account of the patient's situation, he may not pause but instead immediately move to obtain some specific information with questions.

There are a few "don'ts" with regard to the use of silence on the part of the interviewer. Most individuals in our society are made uncomfortable by long silences in ordinary conversation. A doctor who overuses silence may be perceived by the patient as cold or distant. Certain individuals, particularly adolescents, do not tolerate silence well. When the interviewer percieves that his silence produces discomfort in his patient to the point of reducing further communication, he should become more active.

## Facilitation

Encouraging communication by manner, gesture, or words that do not specify the kind of information sought is called facilitation. It represents a greater use of authority than silence but still exerts a low degree of control. Since a completely impassive silence on the part of the interviewer is relatively uncommon, silence and facilitation tend to go hand in hand. An interested, attentive manner is, of course, facilitating. Any change of facial expression or posture displaying greater interest or attention is a facilitation. A common mode of facilitation is the nod of the head, conveying, "I'm listening," "I understand what you're saying," or "Go on." This message is encouraging to the patient but can be overused. Inexperienced interviewers frequently relieve their own tension during the interview with what might be called the "head-nodding syndrome." The clinician should also take pains not to nod his head for facilitating purposes when the patient has been expressing a strong opinion. In such instances, his action may be mistaken for approval of agreement.

A similar message is conveyed to the patient with an occasional "mmm-mmm" or by postural shifts toward the patient or into a position of greater alertness. The doctor may also interject short words or phrases such as "Yes" or "I see" without interrupting the flow of the patient's narrative.

Another type of message that is facilitating is the action that conveys "I don't understand." This may be non-verbal, such as a puzzled look, or a verbal statement of confusion on the order of "I don't follow you" or "I'm sorry, but I don't understand."

When a patient has stopped or appears to be about to stop discussing a topic and the interviewer wants more information, he also may encourage the patient to continue by repeating his last few words. This may be done with the inflection of a question or merely as a repetition. For example, either "the last few days" or "the last few days?" will invite the patient to continue. Another verbal facilitation is a brief summary of what the patient has been saying. This indicates that you have understood him and are interested in further information. A brief summarizing remark will usually encourage the patient to continue, without explicitly directing him to do so or specifying what subject he should discuss.

Facilitation can also be used to return the patient to a topic previously introduced. This is done by referring back to a phrase previously used by the patient which indicates the matter of interest to the clinician. For example, in the course of describing her child's respiratory complaints, a mother may mention that her child has had a fever and then go on without elaborating. After she has completed her description, the physician can then say, "You say Johnny has had some fever?"

Facilitation, then, evokes communication by suggesting to the patient that the doctor is interested in what the patient is saying and is encouraging him to continue. It may also suggest, but not require, that the patient explain or expand on something he has said. A good interviewer with a normally communicative patient should be able to gain much of the information he needs by attentive silence and facilitation. When the doctor senses that the patient is not speaking freely and clearly, however, he should consider making a confrontation.

## Confrontation

In confrontation the interviewer describes to the patient something striking about his verbal or non-verbal behavior. Here the clinician exerts a little more control over the interview than he does in facilitation. Facilitation is a suggestion to the patient that he elaborate on a topic he has introduced. Confrontation directs the patient's attention to something that he may not be aware of--or, at best, be dimly aware of. As a result, a confrontation very often has the effect of introducing a new topic. Examples of confrontation are: "You look sad," "You seem frightened, " "You sound angry," "I notice that you have been rubbing the back of your neck."

Like permitting a silence confrontation poses a difficult problem for the beginning student of interviewing. Students are often self-conscious about using it. In ordinary casual social conversation one does not call the attention of the person with whom one is talking to striking aspects of his manner or behavior of which he is probably unaware. To do so would usually be considered impolite. Very often, too, confrontation is a hostile act; very often it is used in heated controversies. Since confrontation is not part of one's ordinary repertoire of social behaviors, one must develop through practice its use as an effective expression of sympathy or support during an interview.

One situation in which a confrontation is useful has been previously alluded to, that is, when the interviewer observes that the patient is having difficulty in providing information. Some of the possible reasons for this have already been discussed. It was suggested that if there is a pause during which the patient's discomfort has become evident and, perhaps, its nature revealed, a confrontation is in order unless the patient ends the silence by describing his difficulties. The form of the confrontation will depend on what the doctor has observed. Often useful are such comments as "You seem to be having a good deal of difficulty telling me about this" and "You appear quite uncomfortable." The patient who gives brief answers without elaborating may respond to "I notice you say very little except when I ask you questions." A common response is "Oh, I didn't know you wanted me to go on."

Note that the confrontations above describe how the patient appears to the interviewer. They are based on what he has observed. They do not make inferences about the patient's motives or his specific emotional state. It is of course possible that the interviewer has been incorrect in ascribing discomfort to the patient. In this case the remark will give the patient an opportunity to explain the difference between the clinician's perception of his behavior and his own. Such an explanation usually provides useful information.

The confrontation is not formulated as a question. At first glance, it might seem more efficient to ask, "Why are you uncomfortable?" or, "Why do you have so little to say?" There are several reasons for avoiding such questions. First, they assume that the physician is correct. A question puts more pressure on the patient to agree with the doctor than a mere statement of the doctor's observation does. Second, a direct question also requires that the patient make some reply. The patient may not have developed sufficient trust in the doctor to reveal the required information. He may make an evasive partial, or even a false reply. Third, the patient may not know or be able to formulate the answer to the question. Feeling forced to reply, he gives a misleading or uninformative answer. The question "Why?" asks for a causal explanation. Many persons, especially among the lower socio-economic classes and the culturally deprived, do not think in terms of intra-psychic causes for their behavior or problems, and this is the realm of causation to which the doctor is usually referring. Even more important, a complete response to such a question would take the patient to his genetic endowment, his socialization from infancy to the present, the set of circumstances under which he is living, and what is happening in the interview situation. Asking why allows the patient to select some plausible "cause" out of that part of these data which are available to him. His explanation may very well be what he thinks the clinician believes or wishes to hear. This often leads to mutual acceptance of an explanation which appears plausible to the interviewer but which may or may not be either accurate or valid. In pointing out the patient's communicative difficulties the doctor is attempting less to discover their causes then to permit the patient to express the feelings he is then having. This expression may be sufficient in itself to permit the patient to continue; if not, the doctor may be able to assist the patient in continuing once he has listened to this expression.

Another situation in which confrontation is useful occurs when the patient's non-verbal behavior communicates something to the interviewer that the patient is not talking about. For example, a housewife may be describing some set of physical symptoms, and her doctor observes her dejected posture, sad look about her eyes, her low and monotonous voice, and her twisting fingers. By some remark like "It strikes me that you look very sad" the doctor responds to her non-verbal rather than her verbal communication. Slightly reddened eyes or trembling of the chin or lips may indicate that the patient is on the verge of tears. A sympathetic confrontation such as "You look as if you are about to cry" may offer the patient an opportunity to give vent to her feelings of despair by opening weeping. This may have a most valuable therapeutic effect. Physicians in particular tend to avoid situations that encourage a patient to cry for fear the patient will later be ashamed or embarassed about it. This fear very often stems from the doctor's own feelings about the shamefulness of crying. If the doctor responds to the weeping patient tactfully, it is very unlikely that the patient will feel ashamed or embarrassed.

It is appropriate, too, to confront a patient when his voice, posture, bodily movement, or facial expression betray emotions such as anger or anxiety. One can say, "I get the impression that you are angry," or "You sound angry." To an anxious patient, one can say, "You look worried," or, "You seem tense," or one can remark on the behavior which betrays tension or anxiety by saying such things as "I notice you're chain-smoking" or "You're trembling." All such remarks tend to evoke a freer expression of feelings from the patient. Valuable information is derived and other needed information can be obtained more expeditiously after the patient's expression of his despair, fear, anger, or other strong feelings. Lastly, if the clinician handles the situation sensitively, the patient will feel increased trust and confidence.

A particularly appropriate time to confront a patient is when his verbal and non-verbal behavior are clearly incongruous. For example, a patient may speak about very sad things in an indifferent manner, about insults or gross injustice without displaying anger, or about comfortable circumstances and happy events in a mood of dejection. A comment on these discrepancies may lead to valuable information about the patient's difficulties and especially about his conflicts.

A confrontation is also appropriate when there are inconsistencies in the patient's story. This almost always leads to valuable information.

There are few cautions to be stated about confrontations. In ordinary conversation, when we speak of confronting someone, we often mean a hostile accusation. This term often has an unpleasant and unnecessary connotation of anger, even though there are many types of helpful and positive confrontations. When confrontations are made in an interview they should reflect sympathetic interest in the patient. Sometimes the interviewer's irritation with some behavior of the patient may be the cue that calls this behavior to his attention, but it is his interest in this peculiarity of behavior and in furthering the goals of the interview that should prompt and be expressed in the confrontation. A second caution concerns the overuse of confrontation. Even though the patient is confronted in a sympathetic manner, he may feel criticized if he is confronted too often. Confrontations can develop a nagging quality. No more than one or two confrontations about the same or related observations are appropriate in any interview.

## Questions

The question, which could be called directive evocation,[6] requests information and specifies the area of information desired in the response. This is the highest use of authority and it exercises the greatest degree of control thus far discussed. Open-ended questions vary in the degree of authority they represent depending on how closely they specify the area in which the reply is expected.

Questions that require a very specific answer are rarely appropriate if the interviewer does not know how he will use the information in arriving at a decision. If direct questions are properly phrased, answers will most often be brief but high in information content.

Even greater control is exerted when the question is so phrased that a yes or no answer is called for. A similar form is the multiple choice query in which the interviewer specifies a list of specific replies he expects the patient to choose from: "Does this pain come on before, after, or during meals?" These two types of questions we may term check-list questions since they verbally offer the kind of question which may be answered by checking off a pre-printed response on a questionnaire.

Check list questions are generally to be avoided in an interview. Both types tend to stop the interchange. The patient "checks-off" the reply and waits for the next question. Furthermore, both types tend to suggest that the interviewer is not interested in information which does not fall into the categories provided and expects the patient to "pigeon hole" his reply categorically. More communicative patients may overcome this suggestion and provide relevant information not requested, but the interviewer should not rely on this when formulating questions. It is particularly difficult to create good multiple choice questions spontaneously. The categories should be exhaustive and mutually exclusive. If all possible alternatives are not offered, bias is introduced. If all alternatives are presented the question is likely to be so complex that it confuses the patient. Multiple choice questions are, therefore, best given in written form. Questions represent the interviewing behavior most likely to produce biased information. A discussion of ways to avoid bias will be found in Chapter 4.

At what points in the interview is it wise to use direct questions? The first is any time on cannot get needed information with a lower degree of authority. The second is when the broad outlines of the story have emerged and specific information about details is needed. These include the review of systems, inquiry into past illnesses, and parts of the mental status examination. Chapter 4 will deal with these aspects of the interview.

*Direction*, the highest use of control, refers to statements or actions that indicate, instruct, or demand of the other what he should do in such a way that an expected compliance is clearly indicated. Directions to speak, such as "Tell me more about that," exert the full force of the doctor's authority. However, the direction cited does not limit the range of information that the patient will give to anything like the degree that a direct and highly specific question will do so. Thus, directions, too, can allow a patient considerable latitude in what he says, though little latitude in the topic he speaks about.

Somewhat less control than with either questions or directions is exercised when the interviewer makes a *suggestion*. A suggestion is a subtle direction or advice which may guide the patient's thinking or behavior. Because of the authority of the clinician it will have much more effect on the patient than the same words would have in a different setting. Suggestion is the commonest way of biasing information, for this reason. This can be done in several ways. One is by the wording of the question. Another is by shifting topics, which may say to the patient, "That's not important--no more about that." It can also be done by interpreting what the patient has said, or by mentioning a tentative diagnosis. Suggesting a pattern of pain or a symptom must be avoided in diagnostic interviewing. However, suggestion may be helpful in treatment; it is probably the basis of the placebo effect.

## Support and Reassurance

In the first part of this chapter, we mentioned that trust and confidence in the clinician is built when, among other things, the patient is offered support. This is also true of reassurance, when appropriate and correctly timed. The clinician's ability to be appropriately supportive and reassuring helps create an atmosphere in which the patient is encouraged to communicate. It also helps to promote the continuity of the relationship.

*Support* refers to any act which communicates the interviewer's interest in, liking for, or understanding of the patient or which promotes a feeling of security in the relationship. Examples of supportive statements are: "I understand" and "That must have been very upsetting." A summary of what the patient has just said that conveys a sympathetic comprehension is supportive.

One of the most important times to express support is after the patient has expressed strong feeling. After a confrontation to which the patient has responded with weeping, or the expression of hitherto tightly controlled fear or anger, support is most important. It increases the solidarity of the relationship and helps the patient to continue his account.

It must be clearly understood that supportive words without a supportive attitude on the part of the interviewer will sound hollow and will fail to accomplish their intended purpose. Without a genuine interest in the patient, a feeling of friendliness, and a desire to be helpful, supportive words are simply not supportive.

Reassurance includes words or acts which tend in the direction of restoring the patient's sense of well-being, worthiness, or confidence. When patients are very frightened, a reassuring remark may have a remarkably helpful effect. As with support, if the words are reassuring but the clinician's attitude does not convey reassurance, the attempt will fail. To be effective, reassurance must be based on evidence or fact and be genuine. Cliches are rarely reassuring.

Since reassurance depends on acceptance of the doctor's authority, reassurance should not be given in a way that creates unreasonable expectations. Staying close to fact is the best way of avoiding this. The clinician can reassure by citing what he has learned up to that point and how it can be interpreted. On the other hand, stating "everything will be all right" or "There is nothing to fear," unless the evidence clearly supports such a statement, is a poor use of reassurance. The statement "You are making satisfactory progress" is reassuring only if it is based on good evidence that the patient can understand.

## 4. NON-VERBAL COMMUNICATION

Throughout the interview, when the patient is speaking or silent, he communicates simultaneously at two levels. One level, the more obvious verbal or lexical communication, has so far been the primary focus of this chapter. The other, usually referred to as non-verbal communication, has been popularized as "body language."

An early systematic study of body language was made by Charles Darwin, who published in 1872 The Expression of the Emotions in Man and Animals.[8] Darwin studied the behavior, posture, and facial expressions that accompany emotional states. He viewed them as involuntary, instinctive communications that can be easily understood. Weeping, for example, has a communication function, that of summoning help. He studied the non-verbal accompaniments of such emotions as anxiety, grief, and despair and used photographs to illustrate his contention that these facial expressions serve as universally understood non-verbal signals.

In addition to these psycho-biologically determined expressions which appear to be universal, many non-spoken communications of emotions, including gestures, inarticulate sounds, facial expressions, and body movements, are learned at an early age by those who share a given culture. Such communications may be thought of as having a vocabulary consisting of gestures with specific meanings. Even the space a person places between himself and another and the way he uses time (in the sense of lateness or promptness or speed of movement) have meaning or communications. Hall[9] calls this "the silent language."

How may this silent language be perceived in the data-gathering process of the interview? Since data about the emotional status of the patient can be obtained from both verbal and non-verbal behavior, it is as important as the patient's verbal account. At times, non-verbal behavior is essential to understanding what the patient is trying to say. Obtaining it requires that the interviewer carefully observe the patient's behavior, including gait, demeanor, posture, facial expression, and tone of voice, throughout the interview and during the physical examination. Taking notes and looking at one's chart or clipboard while writing is a common barrier to "reading" body language. Even more frequent, however, is the simple failure to observe the patient carefully and to heed the communication that is not being provided in words. This may happen because many clinicians are less comfortable with the patient's feelings than they are with "facts," such as descriptions of symptoms, dates, and times of onset. Anger, sadness, resentment, and fear are facts also, but ones with which some clinicians prefer not to deal. Yet they may be as relevant to an understanding of the clinical problem as the more "objective" data.

Some signals may appear in the words used by the patient. For example, a recurrent allusion to something that is never further explained may mean the patient is leaving out something significant. In this case, one might inquire about it using either an open-ended question or a confrontation.

> The patient, very tense while telling his story, alluded to the various physicians he had previously consulted as either trustworthy or not. Thus, he would say, "Then I went to see Dr. Jones. I trusted him," or "I was sent to Dr. Smith. I didn't trust him." The interviewer commented, "I notice that you mention whether or not you trust each physician you refer to." (Confrontation) After a moment's silence, the patient said. "I guess that's a real problem with me." This led to a description of a disturbing experience with a brusque physician several years earlier, after which the patient developed an attitude of suspicion toward all physicians. Having explained this, the patient visibly relaxed. Further interviewing clarified that distrust of persons in authority was a factor in the patient's general tension and anxiety.

When a patient uses one word or phrase repeatedly it often signals an important preoccupation. A discreet inquiry may bring out feelings of worry, despair, depression, or anxiety.

### Facial Expressions

Sadness is often mirrored in the face of the depressed patient. A downturned mouth, lackluster eyes, or a slight quivering at the point of the chin or lower lip are signs of depression. Clenched teeth with bulging masseters indicate tension, sometimes due to anger. A fixed smile implies that the patient is anxious to please you and may be fearful. Sometimes a forced smile is used to mask depression and to fight off a desire to weep. Simply pointing out the smile may help the patient clarify the underlying meaning. Anxiety usually shows in a patient's face as a discernible look of apprehension, often accompanied by rapid shallow breathing. The apprehensive patient often has darting eye movement, looking about the room and usually not maintaining eye contact except for brief periods.

A person's eyes can be quite revealing. Depression shows there. Eye contact that is too intense may occur when the patient glares at the interviewer (anger) or attempts to be seductive (manipulative behavior), expressions which, of course, are not difficult to tell apart. Inability to maintain eye contact may reflect guilt feelings, as when a guilt-laden topic is being discussed. It may also indicate anxiety or the patient's difficulty in coping with his feelings about the interviewer. Normally, when patients are listening carefully or are intent on telling their story, they will look directly at the interviewer but will not appear apprehensive or angry unless those feelings are being immediately experienced in response to what is being discussed. They will not, however, give an impression of staring at the interviewer.

### Posture

The patient's posture communicates something of his attitude toward you, usually his dominant emotion. Posture can reflect openness (relaxed arms at sides, slightly slouched in the chair) or a closed, defensive, distrustful attitude (arms closed, hugging oneself, sitting up very straight). Slumped shoulders and a bowed head are marks of depression. Anxiety is often signaled by the patient's shifting about, finger tapping, foot and leg movements, or gripping the arms of a chair with white knuckles.

Note whether the patient leans away from you or shifts his chair to increase the distance, thereby indicating defensiveness or distrust, or leans toward you or moves closer, thus expressing a desire for more intimacy. There are also ethnic differences in the distance from others that one finds comfortable. For example, people from Latin cultures may move closer to you than Anglo-Saxons do.

If a patient's posture reveals belligerence, this attitude must be dealt with, as it can be a deterrent to a successful interview. It is best to call attention to it in a tactful, non-threatening way so that it can be brought out into the open and discussed.

> The patient was a forty-three-year-old construction worker being seen for evaluation in the Rehabilitation Medicine Clinic. The interviewer noticed that the patient's fists were clenched, his jaws tightly clenched and that he sat stiffly erect. The interviewer said, "I can't help but notice how you are sitting. You look like you don't want to be here." "I don't," said the patient and went on to describe, with considerable anger, the great number of examinations he had had and his feeling that he was considered to be either a hypochondriac or a malingerer. After the inter-

viewer reassured him that he held no such attitude and that the ultimate purpose of the interview was to initiate treatment, the patient relaxed and the interview proceeded uneventfully.

## Tone of Voice

We all know that the same words spoken in two different tones of voice may have very different meanings. If asked how one's day has been, a reply of "Just fine," said in a warm and pleasant tone usually means just that; the same words said quickly, tonelessly, and without conviction may really say, "Don't bother me. I've had a bad day and I don't want to talk about it." When interviewing a patient, especially on follow-up visits or after an interval of some length since the previous interview, the response to the usual inquiry about how the patient has been feeling may be just such a brief comment. The intonation of the words may then be the clue to how the patient feels. Itmay also indicate the patient's attitude toward the interviewer or the need for further encounters with health care providers. The interviewer's response is usually keyed more to the non-verbal communication of the patient's tone of voice than to the content of the words. Alertness to the intonation and a simple comment or query about it may open up a whole vein of useful information.

## Gestures

Valuable information about the patient's feelings can be obtained by observing his gestures. These are often involuntary and probably instinctive, though how pronounced and expressive they are is influenced by the culture from which the patient comes. Covering the eyes or mouth may mean, "I don't want to see it" or "I don't want to talk." Reaching out to put a hand on the interviewer's arm or to finger his coat lapel may say, "Listen to me" or "Pay more attention to me." Shrugs, waggling the palm of the hand, or holding the palm outward toward the interviewer are easily read messages that usually emphasize the speaker's words or can substitute for a verbal message. When a patient rubs or repeatedly touches a part of his body, one should comment on or inquire about it. The motion usually means pain or discomfort in that area. Anxiety is often signaled by gestures such as rubbing the chin, pulling at the lip, twisting fingers, or tapping fingers or feet. A typical gesture of the frightened, guilt-ridden, or worried person is the partial elevation of one shoulder or the arm as though preparing to ward off a blow.

## Congruence

Any non-verbal message from the patient that suggests something other than the content of the verbal message or seems to be in conflict with it should be given special attention. As we have said, gestures, facial expressions, posture, and tone of voice are more reliable indicators of feelings and attitudes than words. Since verbal messages are under conscious control, they are subject to censorship and may be used for purposes of persuasion, to mislead others, or to hide facts one does not wish to reveal. But body language is not so easily censored and will usually give reliable indications of the patient's feeling state. Lack of congruence between verbal and non-verbal messages may indicate that something is being omitted, whether deliberately or unconsciously. Thus, the skilled interviewer who notes discrepancy between the verbal and non-verbal messages will inquire about it. An effective way of doing this is through confrontation. For example, "You know, Mr. Smith, you say you feel just fine but you look very unhappy." This will frequently focus the patient's attention on his mood. Much new information may then emerge. When patients have difficulty facing certain problems and are attempting to keep their concerns out of their consciousness, their words may serve to help them do that. Their involuntary body expressions will help you decipher the hidden message and bring the patients to an awareness of problems for which there may be some treatment.

The open-ended interview, in summary, represents a style of interviewing that adds features of the interviewing approaches characteristic of psychiatric and social casework to the traditional medical interview. The medical interview emphasizes data collection and aims for high efficiency in gathering detailed data within limited time periods. The aspects added from mental health interviewing include greater attention to rapport and to the development of the clinician-patient relationship and an attempt to facilitate the emergence of facts rather than their extraction from the patient, thereby creating the opportunity for less biased and more relevant information, both verbal and non-verbal. It relies on a differential use of the clinician's authority, never using more authority than is required to get the needed data, and on the ability of the interviewer, through appropriate support and reassurance, to express his interest in helping the patient.

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# MODULE III: CONCEPTS OF DEATH, DYING, GRIEF AND LOSS

PARTICIPANTS MANUAL

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# MODULE III: CONCEPTS OF DEATH, DYING, GRIEF AND LOSS

## I. PURPOSE:

The purpose of this module is to assist the nurse in understanding the processes of grief in reaction to loss and developing effective treatment interventions for dying patients and those that are left behind.

## II. CONTENT:

The module content includes the following topics:

### Section A: The Impact of Philosophical and Cultural Attitudes Towards Death

- The impact of death on life
- Cultural attitudes towards death and the variables that have influenced them in America

### Section B: Grief: The Reaction to Loss

- Definition of terms
- Types of loss
- Theories of grief
- "Grief Work"
- Specific reactions to loss
- Manifestations of grief (psychological, physiological and social)
- Forms of grief reaction
- Factors influencing grief (psychological, physiological and social)
- Abnormal grief
- Factors influencing abnormal grief (social and psychological)
- Symptoms and behaviors of abnormal grief
- How to help the griever
- Wakes, funerals and other mourning rituals
- Grief and children

## Section C: The Dying Patient

- Death as a unique crisis situation
- Tasks of the dying patient
- Grieving and fears of the dying patient
- Defense mechanisms of the dying patient
- Variables influencing the response of the patient
- The issues of acceptance, withdrawal and detachment and hope
- The concept of "appropriate death"
- The nurse-patient relationship when the patient is dying
- Helping the dying patient
- Death across the life cycle: identity tasks, conceptions of death and issues as a terminal patient

## III. LEARNING OBJECTIVES

- Identify four modes with which people provide themselves with a sense of immortality
- Define "grief", and "mourning" and "bereavement"
- Define the two types of loss and give two examples of each type
- Define the three tasks of "grief work"
- Identify the three general phases in the psychological manifestation of grief
- Identify at least four of the physiological manifestations of grief
- Identify at least three psychological factors influencing an individual's grief reaction
- Define "anticipatory grief"
- Identify at least five symptoms indicative of unresolved grief
- Identify and describe at least three social and psychological factors influencing an individual's failure to grieve
- Identify at least three ways to help a griever

- Identify at least four things not to do in helping a griever
- Identify at least two "fairy tales" told to children about death and the harmful effects of each
- Identify at least three things to do when telling a child about the death of a loved one
- Identify at least four tasks of the dying patient
- Identify the four types of death an individual undergoes
- Identify at least three emotional reactions to facing one's own death
- Identify at least four fears of the experience of dying
- Identify the three types of defense mechanisms used by terminally ill patients and give an example of each
- Define and identify the four criteria of an "appropriate death"
- Identify the three levels of understanding toward which communication with the terminally ill patient should be directed
- Identify at least three responsibilities of a caregiver in working with the terminally ill patient
- Identify at least four ways in which to help the patient have a better death
- Identify at least one identify task, conception of death and issue as a terminal patient for each of the seven age groups across the life cycle

## IV. PERSPECTIVE

The participant manual is divided into three sections. Section A is designed to acquaint the participant with the impact on our lives of our knowledge of our own mortality. It seeks to clarify how our response to death influences our response to life. It attempts to foster the participant's own examination of death attitudes and feelings in order to make the participant more aware of them as determinants of lifestyle and manner of working/relating with dying patients.

Also included is a section designed to provide the participant with a cultural framework for interpretation and appreciation of the American individual's response to death. Religious, cultural, ethnic and social norms and proscriptions are discussed as influential variables in providing structure and perspective to individuals. The impacts of a death-denying attitude and the factors which have fostered it in our society are addressed as further variables of the social-philosophical matrix from which an individual's response to death arises.

Section B is the most critical. It focuses on the issues, processes and dynamics of loss. The topic of loss is taken as the main issue in this and the succeeding sub-modules. If the participant can grasp the concepts within this sub-module, then the issue of the dying patient is understandable as a unique aspect of the same situation of loss. It is hoped that the instructor will continually make this point and will illustrate how grief is a natural reaction occurring in response to all losses, not relegated solely to a reaction after death. In this way other losses of patients will be able to be understood by the participant as involving grief processes and requiring conceptualization of them as such, with a consequent response based on therapeutic interventions appropriate for a griever. The issue of children and death is discussed with respect to the similarities and differences between adult and child responses to loss.

Section C focuses on the unique situation of the dying patient. It is presented within the framework of a loss experience, with the idiosyncratic difficulties and processes of dying delineated. Continual attention is paid to therapeutic intervention and the nurse-patient relationship in an attempt to foster a "mind set" for communication and interaction between the participant and subsequent patients.

# MODULE III: CONCEPTS OF DEATH, DYING, GRIEF AND LOSS

## A. THE IMPACT OF PHILOSOPHICAL AND CULTURAL ATTITUDES TOWARDS DEATH

### The Issue Of Self-Mortality

Throughout the history of mankind, the individual has been concerned with the issue of self-mortality. From the consideration of this topic has sprung the disciplines of philosophy, religion, and science. The human condition of limitation and finitude, and the fact that human beings are cognizant of this condition, bears heavily on the mind and spirit of humans as a species. The aforementioned disciplines are examples of the search for control and predictability in coping with the human condition.

The human being is the only animal that can conceive of its own existence, and hence, its non-existence, i.e., death. This knowledge influences the experience and course of life. Much of "how-I-live" is determined by one's response to "I-will-die."

The existentialists have long proclaimed that the posture one assumes towards death influences the quality of one's life. Psychotherapists and philosophers note that the way in which an individual orients him/herself in life (e.g., world-view, defenses, attitudes, psychopathology) reflects his/her responses to the threat of death and its part-aspects (e.g., separation, loss, lack of control, etc.)

Our life, as we know it, would be inconceivable without the tacit assumption that it must end. Such things as reproduction, emotion, competition, and ambition would be pointless if there were never any death (Verwoerdt, 1966). The very fact that people are finite and have only limited time makes the quality of life all the more poignant and meaningful. If people were immortal there would be no reason for aspiring, hoping, striving, and attempting to make meaning out of life, for existence would continue ad infinitum and the quality and value of the experiences of life would pale in intensity in an endless supply of tomorrows with limitless opportunities.

Koestenbaum (1976) has delineated the importance of death in our lives:

- We need death in order to savor life
- Death is an 'invention' needed and therefore created for the sake of feeling alive
- Death puts us in touch with the sense of a real, individual existence
- Death makes possible decisions for authenticity--that is, courage and integrity
- Death gives us the strength to make major decisions
- Death reveals the importance of intimacy in our lives
- Death helps us to ascribe meaning of our life retroactively, a useful concept for older people
- Death shows us the importance for ego-transcending achievements
- Death shows us the path to self-esteem. It gives us the capacity to do something important

However, the threat of the negation of the self and all that is valued, which is most often prompted by thoughts of death, demands response. Human beings are future-oriented animals. To conceive that at some time there will be no future arouses anxiety. This anxiety, itself a response to death, also may initiate other subsequent responses. It is these responses which influence the quality, experience, and course of human life as we know it.

The human condition of death and limitation, and the implications derived from this condition, are stimuli to which all people are subjected and to which they react in response. The reactions may be subtle or blatant; nevertheless, each individual (unless severely organic) entertains a relationship with death. The relationships may range from complete denial of the fact that the individual will die, to complete and existential acceptance of death. The responses to this relationship of an individual and his/her ultimate death pervade both experience and existence.

Death is the ultimate threat in the presence of which the individual constantly exists. The coping mechanisms employed to deal with this threat are integrated with other behaviors in the individual's repertoire throughout the life experience. A person's response to death will be a significant influencing variable for other aspects of life. Several examples serve to illustrate: The parent who cannot accept the fact of his own mortality will avoid the topic of death at all costs. The child's questions around life and death, living and dying will be ignored or given reproval. Wakes and funerals will be missed. The individual will postpone making a will or getting a yearly physical check-up. Discussions about death or death-related topics will be discouraged and/or left unfinished. The individual will minimize separations and losses. In sum, this individual will conduct life in such a manner as to do his/her best to avoid confronting mortality.

Another type of individual will attempt to master the threat of death through the use of counterphobic mechanisms. Such a person will be the "dare-devil" or the one who disregards the physician's orders and continues to sustain the overactive lifestyle. In all realms of life these people tease and tempt death in a grandiose effort to assert to themselves that they have control over death and that they will be the master of their fates.

A different individual will adhere to the religion that promises an eternal life that death cannot vanquish. To such a person, life has meaning as a portal to the more important afterlife. She/he acts accordingly.

All of these individuals have differing responses to the threat of their own deaths. These responses flavor their lifestyles in unique and idiosyncratic ways. Their views of death and the attendant emotions and defenses arising therefrom influence the quality and experience of their lives in all areas. Experiences that are partial aspects of death (e.g., separation, loss, etc.) and events associated with death (e.g., sleep, illness, etc.) may arouse the same threat of death to the individual and may be responded to in much the same manner as more direct death stimuli.

Therefore, our attitudes and feelings around death manifest themselves in other non-death related experiences and behaviors. Hence our relationship with death is a significant variable affecting our life experiences cognitively, behaviorally and phenomenologically. The fact that we, at some future time, will "not be" renders an infinite amount of ramifications and reactions in the "now." The responses will be diverse; from the individual who denies the human condition and has his/her body cryonically frozen to be brought back at a future time, to the individual who accepts the finitude of life but establishes his/her immortality through the reproduction of offspring or the creation of artistic works, to the existentialist who endeavors to create meaning in the present with disregard for the future. In an infinite number of ways the individual reacts to the knowledge of the fact that she/he will die. These reactions are extremely crucial in influencing the life experience, life style and death style of the individual.

(At this point, please read "Confronting Death-Related Feelings" by Kavanaugh [1972] in Appendix. Note how he legitimizes our having these feelings. They need not preclude our doing effective work with the dying and the bereaved if we are aware of them. It is normal and natural to have less-than-positive feelings about death.)

## Confronting Our Own Personal Feelings About Death

### EXERCISE I

In light of the previous discussions (here and in Kavanaugh, 1972) think of your own feelings about death and the attitudes you maintain about it. Write down some of these feelings and attitudes.

In what ways do they influence your own life style and experience? How does the thought of death affect your life now? (e.g., Are you a "daredevil?" Do you avoid attending wakes?, etc.) Please note these below.

Please share your responses with others and see how many are similar, how many are unique.

How does your interest in Hospice fit in?

In what ways do your attitudes and feelings about death have an impact on the ways in which you deal with terminally ill patients and bereaved individuals?

In what ways could you improve your own effectiveness confronting your own death related feelings and improve your work with dying patients and bereaved individuals?

In what areas do you still need more work?

## Attitudes Towards Death and Cultural/Historical Perspectives

In order to appreciate the individual's response to loss and death, it is necessary to have an understanding of the socio-cultural context within which it occurs. Culture and society act upon the individual by proscribing the norms and mores to be followed, supporting or sanctioning against certain behaviors and actions, and determining the repertoire of responses from which the individual will choose. Any work with the individual in the areas of loss and death necessarily must take into account that individual's social, cultural, religious and even ethnic background. Especially because it deals with the universally important issue of death, the individual is highly influenced by the beliefs, mores, norms, standards, and proscriptions of social-cultural, ethnic, and religious background. What is an appropriate way to respond in one culture may be punished in another. The area of death and response to it is laden with contrast. Behaviors and rituals have developed out of our search to cope with this universal phenomenon. For this reason, there may be more variety in the behaviors evidenced by individuals coping with loss and death, since this reflects the diverse ways in which groups of people have approached and struggled with the issue.

It would be prohibitive to discuss here the many rich and varied differences found among various groups in their attitudes and practices related to loss and death. Instead, an overview of the dominant American attitude toward death will be presented, since this will most directly influence the responses of individuals with whom you will work. Such an overview obviously precludes discussion of the finer ethnic, cultural, and religious differences found within this one society.

### Death in American Society and Culture

In his book "Man's Concern with Death" Arnold Toynbee (1968) wrote:

> From the moment of birth there is the constant possibility that a human being may die at any moment; and inevitably this possibility is going to become an accomplished fact sooner or later. Ideally, every human being ought to live each passing moment of his life as if the next moment were going to be his last. He ought to be able to live in the

> constant expectation of immediate death and to live like this, not morbidly, but serenely. Perhaps this may be too much to ask of any being. (p. 259)

For anyone who has surveyed the American attitude of death, it is an unequivocable fact that the above is indeed too much to ask of persons in American society and culture today.

There exist three general attitudes constituting three socio-cultural responses to death. All societies fit into one of these patterns of responses. A society's response to death is a function of how death fits into its teleological view of life. The three general responses are: death-accepting, death-defying, and death-denying.

Primitive, non-technological societies are usually *death-accepting*. The people in these societies view death as an inevitable and natural part of the life cycle. There is an integration of dying and related attendant behaviors into the everyday patterns of living and life. Examples include the Fiji Islanders, Trobrianders, etc.

*Death-defying* societies are those such as in early Egypt. Here the populace refused to believe that death would take anything away. Hence, pyramids were built to contain all the Pharoah's wives and money and possessions for the world after death. Death itself would not deprive the Pharoah. He would vanquish it.

The United States today is a perfect example of a *death-denying* culture. There is a refusal to confront death and there are instead contrivances for coping with it. There is the attitude that death is antithetical to living and that it is not a "natural" part of human existence.

Americans go to great lengths to shield themselves from the realities of death. Take for example the fact that the vast majority of Americans no longer die in their own homes, but are sent to nursing homes and hospitals to die, away from their own familiar environment, family, and friends. True, because of this, other family members need not be made uncomfortable by watching their loved one die, but for the dying individual death becomes lonely, mechanical, and dehumanized. At the very moment that people most need the comfort of human companionship and love from family, they are isolated in the hospital room to await death alone and unassisted.

Dr. Kübler-Ross paints the picture of a more natural death in her book, On Death and Dying (1969):

> I remember as a child the death of a farmer. He fell from a tree and was not expected to live. He asked simply to die at home, a wish that was granted without questioning. He called his daughters into the bedroom and spoke with each one of them alone for a few minutes. He arranged his affairs quietly, though he was in great pain, and distributed his belongings and his land, none of which was to be split until his wife should follow him in death. He also asked each of his children to share in the work, duties, and tasks that he had carried on until the time of the accident. He asked his friends to visit him once more, to bid good-bye to them. Although I was a small child at the time, he did not exclude me or my siblings. We were allowed to share in the preparations of the family just as we were permitted to grieve with them until he died. When he did die, he was left at home, in his own beloved home which he had built, and among his friends and neighbors who went to take a last look at him where he lay in the midst of flowers in the place he had lived in and loved so much. In that country today there is still no make-believe slumber room, no embalming, no false makeup to pretend sleep. Only the signs of very disfiguring illnesses are covered up with bandages and only infectious cases are removed from the home prior to the burial.
>
> Why do I describe such "old-fashioned" customs? I think they are an indication of our acceptance of a fatal outcome, and they help the dying patient as well as his family to accept the loss of a loved one. If a patient is allowed to terminate his life in the familiar and beloved environment, it requires less adjustment... The fact that children are allowed to stay at home where a fatality has stricken and are included in the talk, discussions, and fears gives them the feeling

> that they are not alone in the grief and gives them the comfort of shared responsibility and shared mourning. It prepares them gradually and helps them view death as part of life...(p. 5-6)

As can be seen Dr. Kübler-Ross is attempting to stress the importance of treating death as a natural ingredient of life. The death of the farmer in Switzerland she describes would be all too foreign to Americans. Here we go to great expense to avoid the fact of death. We try to have the dead one look as though still alive. We note how "natural" the dead one looks while residing in the "slumber room." We use terms like "pass on" and "at rest." We send the children away because we think they are too young to understand. In effect, we attempt to deny the fact the individual has died. Worse still, we perpetuate our denial in the young by such lies as "Mommy has gone to sleep." There is little open communication about the topic. It is strikingly apparent that Americans will go to practically any extremes to avoid accepting death for what it is--a cessation of life, a natural part of the life cycle.

Clearly, the time has come for Hospice!

Herman Feifel, in his essay "The Meaning of Death in American Society: Implications for Education" (1971) traces some of the reasons why it is so difficult for Americans today to accept death. He contrasts today with the Middle Ages when death was viewed as the emergence into a new life. The Christian idea of death as a life, albeit changed from before, was prevalent. Death was the reunification with the Creator; death would carry one to a final reward.

Today, with decreasing family integration and a decline of many primary group interactions, plus the upsurge in technology and its resulting depersonalization and alienation, we find "a waning of providential faith, death no longer signals atonement and redemption as much as man's loneliness and a threat to his pursuit of happiness. Fear of death reveals less concern with judgment and more with total annihiliation and loss of identity." (Feifel, 1971). All of this occurs at a time when men and women find themselves losing command of many of their communal relationships. The resulting loss signifies a lack of that which could serve to bolster our sense of continuity or help us to transcend death in some sort of meaningful fashion.

Lifton (1968) in discussing "Death in Life: Survivors in Hiroshima" has come to some of the same conclusions as Feifel in delineating what has lead the American culture to increased difficulty in dealing with death. He describes six variables:

- Urbanization. Individuals are increasingly removed from nature and witnessing the life/death cycle.
- Separation of the aged and persons close to dying. These individuals are segregated away from the general populace into nursing homes and hospitals, making death a more foreign experience and one to elicit the fear of being alone since it will imply such separation.
- Trend toward the nuclear family. With the absence of the extended family comes increased vulnerability to be devastated and left without support following a death of a loved one, and an absence of the opportunity to see aged relatives die and experience death as a natural part of the life cycle.
- Secularization from religion. Religion used to: minimize the impact of physical death by focusing on the hereafter; endow death with a special meaning and purpose; and provide for a future and immortality. There has been a marked loss of these coping mechanisms with the decline in religion.
- Advance in medical technology. This has given man more of a sense of control. There is less of a need for a system of thought which makes meaning out of death (i.e., philosophy and religion). It has "promised" us immortality through cryonics. However, it has enveloped us in torturous bio-ethical quandries (e.g., definition of death, euthanasia). All of these "advances" have compromised our ability to understand death as a natural part of human life.
- Mass death. Previously if the individual contemplated his/her own death it could be assumed that it would cause a ripple in mankind, signifying some degree of importance. With today's constant threat of mass death and nuclear destruction however, this is absent. What good will it do to leave something behind if there is no world left to be aware of it? Additionally, our sensitivities have become blunted to

> individual death. We learned to feel "good" that only fifteen men died in Viet Nam instead of thirty on a particular day. In the past there would have been a time when just one death would have been more horrifying.

Lifton posits four modes which offer us comfort in dealing with death and provide some form of immortality:

- The *biological* mode allows us to prolong ourselves into the future through our children. Our very genes and memories will be carried on through the projection of ourselves by our heirs.
- The *social* mode provides for our lives to have direction and meaning if we can leave something worthwhile behind us. This usually comes to fruition through one's work or creative endeavors.
- The *religious* mode provides a clear future in an immortal hereafter.
- The *natural* mode allows us to be part of nature. The decomposition of our bodies will nourish further growth in nature and we will not forever be destroyed because of our spot in the cycle of the chain of life.

Consideration of all of these variables will provide a more complete understanding of the social and cultural framework out of which most of the Hospice patients will operate. An appreciation of this is important because of the strong influence that society and culture will have upon the responses of the individual. Responses to loss and death are no exception.

## B. GRIEF, THE REACTION TO LOSS

### Definition of Terms

The terms "grief," "bereavement," and "mourning" are often used interchangeably. Actually, however, they have quite distinct meanings and implications. The following definitions will be used in this text.

- *Grief: A process*. The emotional reaction to the perception of loss. This implies that: (a) grief is a *continuing* development involving many changes; (b) grief is a *natural* reaction; and (c) grief is a reaction to the experience of *many kinds* of loss, not necessarily death alone.

- Mourning: The cultural response to grief. This implies that there is no one style of grief, but that grief is a reaction which, like other reactions, may be socially and culturally influenced.
- Bereavement: The state of having suffered a loss.

## Types of Losses

Grief is the normal reaction to loss. Each individual encounters loss throughout the entire life cycle. Loss is a natural part of our existence: children lose baby teeth and childhood naivete; a pet kitten dies; a lover is abandoned; an amputation is performed; a brother moves away; a wife succumbs to cancer; and retirement occurs. All of these are losses. Losses may be of two kinds:

- "Real" or "physical"
- "Symbolic" or "psychosocial"

Examples of a "physical" loss include losing a desired possession, or moving to a new city. Examples of a "symbolic" (psychosocial) loss would include getting a divorce, or losing status because of a job demotion. (Usually a symbolic loss is not identified as a loss per se and people do not realize they need to take the time to grieve and deal with their feelings about it. Nevertheless, it definitely is a loss and will initiate a process of grief just like a physical loss will. We will see that one of our most important tasks is to help people identify and acknowledge their symbolic losses in order that they can appreciate and realize that a loss has occurred and that they need to grieve for it.) Over and over we must confront issues of loss. To a greater or lesser degree the process of grief occurs in reaction to each of these losses. Grief is that process which will allow us to let go of that which was and be ready for that which is to come.

If we think about it, it becomes apparent that many of the situations which have been difficult for us in our lives have entailed our having to experience some kind of loss, whether it be "phsyical" or "symbolic."

## EXERCISE II

Write down the three most difficult situations you have had to deal with in your life.

Have any of these involved a "physical" or "symbolic" loss?

If so, which of them?

Please make a list of some of your reactions at the time when you were faced with the situations.

Please note your reactions after you dealt with the situations and since that time.

Therefore, it is important to realize that grief is not only relegated to the reaction after death. As nurses, you are constantly in situations where people must cope with loss. Just being in a hospital environment or in a Hospice entails the loss of one's familiar environment. Being sick and dependent upon others to take care of you is a loss. The loss of independence also means that there is a loss of control for the individual who now is in a patient role. The illness of cancer brings with it a number of attendant losses. These may include: loss of autonomy, loss of body functions, loss of body parts, loss of social contact, loss of self-esteem, and loss of mobility. As can be seen, these losses are both physical and symbolic (psychosocial) in nature. Each of these losses have an impact upon individuals and will prompt some form of grief reaction. The loss of a breast is not necessarily any more or less of a loss than the loss of social contact. The meaning and extent of the loss will differ for each person according to their own individual personality and characteristics. As nurses there are several things that must be remembered:

- That cancer involves a number of losses both physical and symbolic in nature
- That each of these losses prompts its own grief response
- That the importance of a loss will vary according to its meaning to each individual

## Two Landmark Theories of Grief

In 1917 Sigmund Freud published his classic paper "Mourning and Melancholia" in which he undertook to define the normal process of grief. He wrote that mourning is:

> the reaction to the loss of a loved person, or to the loss of some abstraction which has taken the place of one, such as one's country, liberty, an ideal, and so on... It is also well worth notice that, although mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful.

This illustrates for us several important things about grief. First, it asserts that grief is prompted by loss and that this loss need not only involve a death. Second, it notes that grief is a normal and expectable process. Third, it implies a self-healing aspect of grief which, under normal conditions, will be resolved. The four "grave departures from the normal attitude to life" constitute the major characteristics we normally associate with grief and include:

- A profoundly painful dejection
- Cessation of interest in the outside world (insofar as it does not recall the lost loved one)
- Loss of capacity to love
- Inhibition of activity with turning away from any activity not connected with thoughts of the lost person

These are viewed as pathognomonic of the grief process and the expectation is that, with time, they will be overcome and resolved by reality, with interference of the natural process being useless or even harmful.

In his landmark study after the tragedy of the Cocoanut Grove Fire in Boston in 1944, Erich Lindemann, the pioneer in grief investigation, wrote about acute grief as a normal reaction to a distressing situation and one often cited among alleged psychogenic factors in psychosomatic disorders. It was marked by a definite syndrome with psychological and somatic symptomatology. Lindemann delineated five points that were characteristic of grief:

- Somatic distress
- Preoccupation with the image of the deceased
- Guilt
- Hostile reactions
- Loss of patterns of conduct

A sixth characteristic was evidenced by individuals who appeared to border on pathological reactions--the appearance of traits of the deceased in the behavior of the bereaved, especially symptoms shown during the last illness or behavior shown at the time of the tragedy.

## Tasks and Process of Grief

When Erich Lindemann conducted the first major investigation into the process of grief, he interviewed the relatives of victims in the Cocoanut Grove Fire in Boston, Massachusetts. His description of "grief work" still stands today.

"Grief work" entails the following three tasks:

- Emancipation from the bondage of the deceased
- Readjustment to the environment in which the deceased is missing
- Formation of new relationships

The term "grief work" is an apt one since the process of grief is a strenuous and arduous one. It requires both physical and emotional energy, as do all other types of work. It is no less work than digging a ditch.

One of the major complicating factors in accomplishing one's grief work is that the effect of loss itself resurrects old issues and conflicts for the mourner. Conflicts around childhood dependency, ambivalence, parent-child relations, and security, to name but a few, are stirred by the experience of loss and may mitigate against easy resolution of grief.

The fact that grief is not commonly perceived as "work" often causes difficulties for the bereaved. They are often not prepared for the intensity of their own reactions or do not fully understand the importance of expressing and accepting them. In addition, since others are similarly unaware, they quite often are lacking the social and emotional support necessary to sustain them during their grief work and mourning.

Basically the single most crucial task in grief is "untying the tie that binds" one to the deceased individual. This does not mean that the deceased is forgotten or not loved. What it means is that the emotional energy which the mourner had invested in the deceased is modified in such a way as to allow the mourner to reinvest in others for his/her emotional satisfaction. This is termed "decathecting" or detaching and modifying emotional ties so that new relationships can be established and the mourner is not tied non-therapeutically to an individual who is no longer alive. The work of mourning entails the reviewing of the memories and feelings connected with that which was lost. Not only the actual person/object/ideal must be grieved, but also the mourner's hopes, dreams, fantasies and unfulfilled expectations for it. The successful accomplishment of this task derives from the satisfactory completion of the grief work outlined by Lindemann. The reactions during the process of meeting these tasks are discussed next.

## Specific Reactions to Loss

A number of researchers have delineated the stages they have perceived in grief. A brief overview of several of them are presented here to acquaint the reader with some of the writings in the field. Although these were initially written with specific regard to the loss of a loved one through death, they are discussed here in terms applicable to any type of physical or symbolic (psychosocial) loss.

Lindemann (1944) described three stages.

- The initial stage is one of shock and disbelief which is characterized by the inability to accept the loss and occasionally the absolute denial that the loss has occurred
- The second stage is the working phase of acute mourning which is characterized by the acceptance of the loss, disinterest in daily affairs, weeping, feelings of loneliness, insomnia, and loss of appetite. There is an intense preoccupation with the image of that which was lost
- The third stage is the resolution of the grief process which is marked by the gradual reentry into the activities of daily life and a decreasing image of that which was lost

Bowlby's (1961) theory of grief differentiates three main phases of mourning:

- The first phase is "Protest" which is signified by anger, yearning, denial and weeping
- The second phase is "Disorganization" in which there is despair and depression

- The third phase is "Reorganization" in which the breaved breaks down attachments to that which was lost and starts to establish new ones

In 1970, Parkes summarized the psycho-emotional aspects of grief. He wrote that it was a phasic process which commenced with the "Numbness" phase. This was followed by the second phase consisting of "Yearning," or the attempt to reunite through various means with that which was lost (also termed "Searching") and "Protest," which is evidenced in the restlessness and irritability directed either toward the self or others. In addition, tearfulness, anxiety, tension, and the tendency to treasure reminders and to want to keep a clear visual memory of that which was lost may be apparent. The third phase is "Disorganization" which is characterized by the disinclination to look to the future or to see any purpose in life. Following this there is a gradual return of interests and appetites.

Kavanaugh (1972) posits seven stages in the process of grief. These are self-explanatory and include:

- Shock
- Disorganization
- Volatile Emotions (e.g., Anger and Hostility)
- Guilt
- Loss and Loneliness
- Relief
- Reestablishment

Kübler-Ross (1969) delineated five stages an individual undergoes when coping with imminent death. These have also been used to identify the grief of individuals after a loss, as well as serving to describe the grief of a dying individual engaged in preparatory grief over the loss of self and loved ones through his/her own death. These stages include:

- Denial and Isolation, a period of shock which functions as a buffer against the overwhelming reality of the situation and then gradually gives way to less radical defenses

- Anger
- Bargaining, in which pleas are made to God or the doctors or which is evidenced by the intense preoccupation with that which was lost, in order to forestall the loss for a little while longer
- Depression
- Acceptance

There are numerous other conceptualizations of the processes of grief. They have been written in describing such populations as the dying patient, the divorcing individual, the patient coping with an amputation, and the survivors of natural disasters. Although the theories and conceptualizations may have different names and ostensibly focus on different topics, they all entail loss. They all have the same basic feelings in common, only the labels differ.

Because of this, it is helpful to consider the emotional reactions to grief as fitting within three broad categories: *Avoidance*, in which there is shock, denial, and disbelief; *Confrontation*, a highly emotional stage wherein the grief is most intense and the emotional reactions to the loss are felt most acutely; and *Reestablishment*, in which there is a gradual decline of the grief and there begins an emotional and social reentry back into the everyday world. Any theory of the symptomatology of grief can be collapsed into these three broad phases.

### "Stages" Theory

Before continuing further it is important to address the issue of "stages." There has been much controversy in recent years about "stage theories." The main criticism has centered around the expectation that such a word as "stage" connotes: i.e., that there exists an invariant and sequential process. Adherence to such a belief has resulted in individuals being forced into inappropriate positions, as some caretakers have responded to them in terms of the stages they were "supposed" to be in rather than to the particular needs of the individual at that point in time. Thus, the stage theories have been misused by some who have defeated their purpose by trying to fit the individual to the theory instead of using the theory to gain a better understanding of the individual. All individuals will not have the same experience, need the same interventions, nor follow the same clinical course. As an example, to try to "push" patients through Depression in order to try to get them to Acceptance (to use the Kübler-Ross schema) is not only doing the patient the grossest misservice, since the individual needs are not being attended to, but is also a misinterpretation of the purpose of the theory, which is to provide a general pattern but not suggest an invariant, necessary, or absolute course.

For this reason, the schema presented in this writing is discussed in terms of "reactions" rather than stages. These reactions are colored by the individual characteristics of each person, as well as the pertinent social and physiological factors. (to be discussed below). The reactions do not form rigid phases and the individual will flow back and forth among them in his/her experience. All individuals will not experience all reactions. The reactions are presented here as possible responses to a loss. The listings are not meant to be exhaustive of all possibilities.

## Psychological Manifestations of Grief

### 1) The Avoidance Phase

During this phase there is a desire to avoid the terrible acknowledgment that which was loved is now lost. Depending on the nature and meaning of the loss to the individual, the world is shaken and she/he is overwhelmed by the impact. Just as the human body goes into shock after a large enough insult to it, so too does the human psyche go into shock when confronted with an important loss. It is the natural reaction to the impact of such a blow. During this period the individual may be confused and dazed, unable to comprehend what has happened.

As recognition starts to seep in and shock starts slowly wearing off, denial immediately crops up. It is only natural that the individual would want and need to deny that such a terrible event has occurred. At this initial phase denial is therapeutic. It functions as a buffer by allowing the individual to absorb the reality of the loss a little at a time and serving to prevent his/her being completely overwhelmed by it. It is similar to an "emotional anesthesia" which serves as a protective mechanism for persons who have

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suddenly been confronted with the destruction of the world they used to know.

Disbelief and a need to know "Why?" may appear at this time. There may be an explosion from the more outgoing, or withdrawal or depersonalization from a more introverted mourner.

### 2) The Confrontation Phase

During this highly emotional phase grief is experienced most intensely. The individual has recognized that there has been a loss and the shock has worn off to a great degree. Denial and disbelief may still occur, but a whole host of new reactions arise that spring from the individual's confronting of the loss and its implications.

Anger is a natural reaction occurring when an individual loses someone or something that is valued. Unfortunately, our society does not deal very well with anger and therefore both the mourner and those trying to console the mourner may have difficulty acknowledging and accepting this very natural and expected emotion. Anger is one of the two primary problems one encounters in grief because of this social lack, and guilt is the other. Many times the anger is displaced onto other people, frequently without the griever's conscious knowledge or intent. This anger may be vented at God, the doctors, the person who died, others who have not sustained the loss, and the bereaved self. The anger at oneself may also be the result of guilt (discussed below), loss of control, or frustration.

Guilt is always to be expected following a loss. Because our relationships always contain some measure of ambivalence (i.e., some degree of negative as well as positive feelings) and because our lives, as ourselves, are not perfect (i.e., in even the most perfect relationship there is always something else that could have been done for the other person), guilt will always be a natural concommitant with loss. After a person experiences a loss it is common to think about what "could" or "should" have been done, as well as to feel guilt about the normal amount of "negative" feelings that exist in the ambivalent feelings we all have, to one degree or another.

There are other causes of guilt too. The griever may feel guilty that he is still alive while a loved one has died. The many feelings of grief can prompt guilt. For example, an individual could feel guilt when they recognize their own normal sense of anger at the deceased for having died and deserting them. For some people, the fact that they give vent to their emotions by crying may be enough to resurrect guilt due to the fact that they feel they have "lost control."

*Depression* and *despair* are common reactions to important losses. Many writers feel that it is precisely an important loss which gives rise to any depression. Whether or not this is true, there are definitely numerous symptoms of depression which are usual manifestations of grief. These include: *withdrawal*; *apathy*; *feelings of loss*; *regression*; *dependency*; *somatic problems*; *tearfulness*; *feelings of hopelessness, helplessness, and being out of control*; *ambivalence*; *shame*; *sadness*; *loss of ability for pleasure*; *depersonalization*; *loneliness*; *disorganization*; *lack of concentration*; *confusion*; *a sense of abandonment*, *disinterest* and *detachment*.

There are several common reactions which are a combination of depression and anger. These include *irritability*, *anxiety*, and *tension*.

The *preoccupation with that which was lost* is a natural response to loss. It occurs both as a wish to undo the loss and as a reflection of the internal grief work being done, in which the griever is focusing attention on that which is lost (e.g., the deceased loved one) as he/she begins to detach emotionally from it in order to free attachments for new ones in the future. This preoccupation with that which was lost is often manifested in the bereaved's thinking that they have seen the lost loved one/object or in actively searching for that which has been lost. Numerous things will remind them of what they have lost. Pictures and momentos are clung to. There is some evidence that a significant proportion of bereaved individuals actually experience some type of visual or auditory hallucinations in which they "perceive" that which was lost. (Rees, 1972)

Reactions such as these, and the intensity of other grief reactions, often make the mourner wonder "*Am I going crazy?*" Individuals are scarcely ever adequately prepared for the type and strength of grief reactions they sustain. Because these reactions are so different, unexpected and intense, the mourner may believe that he/she has lost touch with reality.

An additional difficulty is that there are few models or culturally prescribed roles for mourners in our society. This makes it *difficult for the mourner to know how he/she "should" act or feel*. With the absence of such guidelines there is an increase in ambiguity. This ambiguity fosters more stress in a situation which is already overburdened by it, and this may serve to contribute further to the mourner's feelings of losing control and "going crazy."

### 3) The Reestablishment Phase

This phase constitutes a *gradual decline of grief* and marks the beginning of the emotional and social reentry back into the everyday world. Although the old adage "once bereaved, always bereaved" is unquestionable, the mourner learns to live with the loss as emotional energy is reinvested into new persons, things, and ideas. The old loss is not forgotten, but merely put in a special place which, while allowing it to be remembered, also frees the mourner to go on to new attachments without being pathologically tied to the old.

This phase is not an "all-or-nothing" phase, nor are the previous two phases. Rather, it waxes and wanes during the latter period of the Confrontation phase and continues slowly thereafter. It never arrives all at once and for some time it co-exists with many of the previous reactions. *Guilt* often accompanies the beginning efforts at reestablishment as the mourner must cope with the fact that she/he continues to live and experience in spite of the loss. For those grieving as a result of a death this is a particularly thorny issue as they may feel that they betray the lost loved one if they enjoy life without that person.

## Physiological Manifestations of Grief

There are a number of physiological reactions that accompany the emotional reactions to loss. These have been documented most notably by Lindemann (1944) and Parkes (1964, 1970, 1972). The following is a list of some of the more common physiological symptoms which occur in normal grief. A mourner may manifest one or any number of these:

- Anorexia and other gastrointestinal disturbances
- Loss of weight
- Inability to sleep

- Crying
- Tendency to sigh
- Lack of strength
- Physical exhaustion
- Feeling of emptiness and heaviness
- Feelings of "something stuck in throat"
- Heart palpitation and other indications of anxiety
- Nervousness and tension
- Loss of sexual desire
- Lack of energy and psychomotor retardation
- Restlessness and searching for something to do
- Shortness of breath

The important thing to remember is that although we have defined grief as the "emotional" reaction to the perception of loss, there always are physiological concommitants to all emotional reactions. Therefore, grief is expressed through a variety of somatic symptoms as well as psychological ones.

## Social Manifestations of Grief

The experience of grief appears socially in a loss of normal patterns of conduct (Lindemann, 1944) including:

- Restlessness and the inability to sit still
- Painful lack of capacity to initiate and to maintain organized patterns of activities
- Social withdrawal behavior that is antithetical to the establishment of new relations and the alleviation of stress

## Forms of Grief Reactions

The above descriptions delineate normal grief. However, there are a number of other forms in which the grief reaction may be seen. The following list is adapted from Averill's (1968) analysis of Lindemann (1944) and Parkes (1965).

- Normal Grief: A stereotyped set of psychological and physiological reactions in which there are a number of responses which fit under the three general phases of Avoidance, Confrontation, and Reestablishment.

- Exaggerated Grief: An abnormally prolonged grief reaction, frequently with an intensification of one or more of the manifestations of normal grief. Neurotic features, such as undue guilt and identification symptoms, are often associated with this form of grief.

- Abbreviated Grief: A short-lived, but genuine grief reaction due to an immediate replacement of the lost object (e.g., marrying a new spouse right after the first one dies) or to an insufficient attachment to the lost object (e.g., the individual was never really that attached to the spouse in the first place).

- Inhibited Grief: A lasting inhibition of many of the manifestations of normal grief, but with the appearance of other symptoms (e.g., somatic complaints) in their place.

- Delayed Grief: Normal or exaggerated grief may be delayed for an extended period of time, ranging up to years, especially if there are pressing responsibilities to occupy the bereaved (i.e., "pushed aside until later"). A full grief reaction may eventually be initiated by some event related to the original loss, (e.g., a pet's death can trigger a grief response for a loved one who died years earlier, but who had never been mourned because the griever felt he had to be strong to take care of other family members). In the meantime, only an inhibited form of grief may be observed.

- Anticipatory Grief: Many of the symptoms of normal grief may result from an expected loss, i.e., "in anticipation" of it, (e.g., the terminally ill patient and his family). In some cases this may result in only an abbreviated reaction manifested upon actual loss, but this will vary according to individual cases. In some instances, if the expected loss does not occur (e.g., the P.O.W. soldier doesn't die but returns home) the grievers have already mourned in anticipation of the possible loss to such an extent that they have emotionally detached themselves from the individual and no longer feel the same attachments. (This gives some explanation of the high divorce rates in the marriages of P.O.W. soldiers who returned home)

## Factors Influencing the Grief Reaction

An individual's grief reaction will be influenced by a number of factors: psychological, physiological and social in nature.

### I. Psychological Factors Influencing Grief

1) The nature and meaning of the relationship severed or loss sustained will have a profound influence on the grief experience. All individuals will not respond in the same way to the same loss. One needs to appreciate the idiosyncratic meaning that a loss has for a given individual in order to understand the grief experience. For example, the loss of a pet may be painful to many people, but it may be exceptionally devastating to the elderly individual to whom it has meant company and security. Such an individual may grieve more over the loss of a pet than over the loss of a sibling, if the pet has been more important and meant more to the individual. For this reason, it is improtant to attempt to have an understanding of the meaning a particular loss has to a particular individual. Without such an understanding it will often be difficult to appreciate the individual's grief. One's sense of meaning determines what is important in their world and what would constitute a loss to them. To be told that due to medical reasons one's jogging must be restricted to two miles a day may be a small disappointment for many of us, but may constitute a major traumatic loss for the individual who had aspirations of being a marathon runner. Therefore, one can never use their own standards solely in determining the impact of a loss for another individual. Instead, this individual's frame of reference must be employed if we truly want to understand the impact and implications a loss may have.

2) The individual qualities of the relationship lost will necessarily influence the mourner's grief. For example, a relationship characterized by extreme ambivalence may be more difficult to resolve than one which is not as conflicted. If there is a small degree of attachment in a relationship it will be easier to resolve the grief for it than for a relationship in which there is a stronger degree of attachment and there is more lost. Individuals who are strongly dependent upon an individual who dies may sustain more difficulties

than others as they try to part with the lost relationship and establish new ones. Therefore, the psychological nature of the relationship severed and the strength of that attachment will have an influential bearing on the mourner's capacity to complete grief work.

In this context it is important to differentiate between "role-loss" and "object-loss." A role-loss entails a loss of status or function (a symbolic loss), while an object-loss involves the loss of a particular person or object. For example, if a woman becomes widowed she loses her husband (object-loss) as well as her status and function of being a wife (role-loss). In many situations the role-loss, with its attendant alteration in status and function, may be more important in the cause of grief than is the actual object-loss. For example, we are all familiar with people who become quite depressed after their last child gets married. Usually in these cases, it is the loss of being able to parent, to nurture and to be needed that causes the grief and not necessarily the loss of the child per se since that child is still alive. Therefore, frequently we may perceive people grieving and are puzzled since we cannot see an object-loss. In many cases, a role-loss (e.g., retirement) has prompted the grief reaction, which will entail the same processes of grief as would a specific object-loss.

3) The individual's personality, coping behaviors, and mental health will influence the response to grief just as it influences all other responses in life. If an individual has always been one who has run away from crises, then chances are that the same behavior will be evident in the grief situation. In most cases, an individual's personality and past behavioral style will be the best predictor for future behavior. Obviously there are exceptions to this rule, however the coping behaviors that one brings to bear on other stressful situations in life tend to form the repertoire from which individuals usually select coping behaviors to meet the crisis of loss. Similar to the dying patient, the individual will grieve (and the dying patient will tend to die) in the same manner in which the rest of life has been conducted. Additionally, the current state of mental health as well as a past history of depressive illness will play determining factors in the individual's response to the loss since they influence the perceptions, reactions, and coping mechanisms that will define the individual's grief.

4) An individual's past experiences with loss and death will obviously influence how a current loss situation is approached. Such past experiences will not only set up certain expectations, but serve to provide coping strategies and/or defense mechanisms. As with anything else, if a situation has been experienced previously it will be slightly easier to cope with to the extent that it is not as strange as it was the first time it was experienced. By the same token previous negative experiences can influence a griever in a harmful way, just as past positive experiences can assist the griever in coping better with the loss.

5) Just as the individual's personality, coping behaviors, and mental health play a crucial part in determining the grief reaction, so too does the individual's level of maturity and intelligence. These are additional attributes of the individual's personality and, as such, influence the perceptions and reactions following the loss. Maturity and intelligence have been found to be consistently and positively correlated with effective coping skills and with favorable outcomes of stress. The findings are the same with regard to the stress of loss.

6) The characteristics of that which is lost are determinants of the nature and meaning of the loss. With regard to loss through death the characteristics of the relationship severed and the role it played in the mourner's life constitute critical variables in the determination of the mourner's grief experience. Additionally, the age of the deceased and the type of person he/she was will play a large part in the type of reaction that will be manifested by a mourner upon the death. In our society, the death of the young is viewed as a worse loss than the death of the elderly. Hence, grief is usually more intense subsequent to the loss of an adolescent as opposed to the loss of his grandparent. There are, of course, many exceptions to this, but in general, our society (correctly or not) tends to respond in the fashion of decreasing intensity of grief with increasing age of the deceased. We need to be wary of this, however, since it would be wrong to minimize the intensity of a mourner's grief merely because his/her loved one was elderly. We must appreciate the meaning of the deceased to the mourner and be careful not to get caught up in social stereotypes. (e.g., If the deceased was old it is necessarily easier for the mourner.)

There has been some literature which suggests that the death of one's child (irrespective of age) provokes more intense grief reactions than the death of a spouse or parent (Sanders, 1977; Gorer, 1965). It does not make sense to parents that their child should pre-decease them. The normal order of the world appears to have been violated. Again, the role of the deceased in relation to the mourner is a factor in that mourner's grief experience. (See also the discussion on role-loss in previous section on "The nature and meaning of the relationship severed or loss sustained"). However, the primary determinant will be found in the meaning of that relationship to the mourner.

7) Another factor is found in the mourner's perception of the deceased's fulfillment in life. The more the mourner perceives the deceased as having had a fulfilling life, the more readily can the death be accepted and the grief work done. This is an additional reason why the death of the young is so difficult to comprehend and accept, since they have not had the opportunity to have had much of a fulfilling life.

8) The "death surround" contains important variables influencing a mourner's grief. This term refers to the immediate circumstances of the death or loss. This also includes the location, timeliness, reason for the loss and degree of preparation. Ideally, the mourner will feel that the circumstances are appropriate (e.g., the deceased had had a fulfilled life, was older, died in familiar surroundings from an illness that had received the best medical attention possible and the mourner had had the opportunity and time to prepare for the loss and to "finish unfinished business" with the dying person). It is in this area that Hospice is especially crucial in influencing the experiences of the griever as well as of the dying individual. To the extent that the death surround can be accepted by the griever, the grief will be more amenable to management. The converse is also true. The circumstances of one's loss may be detrimental factors exacerbating the emotions of grief (e.g., if one has to deal with a loved one's having been decapitated in a motor vehicle accident it may be more difficult to cope with than if the death had occurred in the person's home with family and friends attending).

9) The issue of "sudden" versus "expected" death is an important one. Much of the research points to the relatively adaptational value and salutory

effects of having had some advance warning and the opportunity to experience moderate amounts of anticipatory grief prior to the actual loss (Fulton and Fulton, 1971; Glick, Weiss, and Parkes, 1974; and Parkes, 1975, 1972). This allows time for "finishing unfinished business" with the patient; preparing oneself for the consequences of the loss; and absorbing the reality of the loss gradually over time.

Fulton and Fulton (1971) identify the four facets of anticipatory grief. They are:

- Depression
- Heightened concern for the ill person
- Rehearsal of the death
- Attempt to adjust to the consequences of the death

As with other situations in life, human beings appear to be better able to cope with stress if they have some preparation for and forewarning of it.

However, some researchers have been concerned that too much anticipatory grief can lead to premature detachment from the dying person (Lindemann, 1944; Peretz, 1970; Travis, 1976; and Levitz, 1977). Others feel that this is a normal part of the process (most notably Chodoff et al., 1964). Still others feel that the duration of anticipatory grief is not significantly related to the severity of the grief reaction (Maddison and Viola, 1968; Clayton et al., 1968; and Parkes, 1970).

Despite the mixed results in the literature, the general feeling is that if individuals can have the opportunity to prepare for an imminent loss (whethor it be a physical or symbolic [psychosocial] loss) they are more equipped to cope effectively with it than if they have had no prior knowledge and the news comes as a complete shock. A well-trained Hospice staff and supportive family can minimize the effects of any premature detachment which would be non-therapeutic for the individuals involved.

## II. Physiological Factors Influencing Grief

1) The potential negative effects of drugs and sedatives may outweigh their usefulness in many cases. Drugs to calm a person down or anesthetize them to the grief experience are non-therapeutic in that they rob the griever from experiencing the pain and realizing the loss they are ultimately going

to have to confront. Oftentimes the bereaved are drugged during the wake and funeral, the precise times in which they should be encouraged to give vent to their emotions. This leaves them having to eventually confront their loss later on, at times in which there may not be social support available as there usually is during the initial period following the loss. The bereaved are already psychically "numb" and the immediate use of psychopharmacological agents to accomplish the same effect is questionable.

This is not to imply that at some point drugs are not a useful tool for the bereaved. Although heavy sedation to block the mourning process is not wise, mild sedation to prevent exhaustion, severe insomnia, and disease resulting from them may be quite therapeutic. Since the bereaved need energy for their "grief work" such medication may be helpful in these areas. Complications of the mourning process (e.g., agitated depression, psychosis, elation, phobic anxiety states, etc.) will require the skilled evaluation of a psychiatrist and may benefit from psychopharmacological intervention, as may other indices of abnormal grief.

2) The nutritional needs of the bereaved need to be monitored. The bereaved require strength to effectively cope with their loss. Inadequate nutritional intake will compromise the individual's functioning. It is not uncommon for the bereaved to be anorexic and, if they do eat, to complain of the altered taste of food and impaired gastro-intestinal functioning. Despite this they must be encouraged to maintain adequate nutritional balance and eating habits.

3) Adequate rest and sleep are mandatory for the bereaved. Some degree of sleep disturbance is normally expected in the grief response. However, a lack of sufficient sleep may predispose the bereaved to mental and physical exhaustion, disease, and unresolved grief. The requisite energy to undertake the necessary grief work may be impaired and a medication consultation would be warranted.

## III. Social Factors Influencing Grief

There are a number of social factors influencing grief. These include the individual's social, cultural, religious, and ethnic background and the individual's external support system and the acceptance and assistance of the members therein. These factors will be discussed in detail in the section "How to Help the Griever" below.

Abnormal Grief

In 1944 Lindemann classified "abnormal" grief reactions into two categories: those which constituted a delay of normal grief reactions and those which represented distorted reactions. Under distorted reactions Lindemann noted the following behaviors:

- Overactivity without a sense of loss
- The acquisition of symptoms belonging to the last illness of the deceased
- Development of a medical illness psychosomatic in nature
- Alteration in relationship to friends and relatives with progressive social isolation resulting
- Extreme hostility toward specific persons somehow connected with the death event, e.g., surgeon, hospital, nurse
- Wooden and formal conduct which masks hostile feelings and resembles a schizophrenic picture
- Lasting loss of patterns of social interaction
- Acts detrimental to one's own social and economic existence, e.g., giving away one's belongings, foolish economic dealings
- Agitated depression marked by tension, agitation, insomnia, feelings of worthlessness, bitter self-accusation and obvious need for punishment. The individual may be suicidal

It is important to note that aspects of these reactions are found within the dimensions of normal grief. The reactions are pathological only when they are carried out to the extreme of a continuum. This serves to identify one of the three primary variables which mark abnormal grief (Siggings, 1966): absence of a grief reaction, prolongation of a normal grief reaction and distortion of the normal grief reaction.

Jackson (1957) feels that there are two conditions which may provoke difficulties in accomplishing grief work and thus predispose one to abnormal grief.

(1) The difficulties may result from the mourner's inability to tolerate the attending emotional distress of grief, and (2) they could arise due to an excessive need on the part of the mourner to maintain interaction with the deceased.

Lazare (1979) has delineated a number of social and psychological reasons for failure to grieve, thus leading to abnormal grief. The following lists are adapted from his work.

Social Factors Influencing Failure to Grieve and Abnormal Grief

- Social negation of a loss: In this situation the loss is not socially defined as a loss, e.g., an abortion, a miscarriage, an infant given up for adoption. Although grief work is necessary, the social support for it is inadequate or nonexistent.
- Socially unspeakable loss: In this case the loss is so "unspeakable" that members of the social system of the bereaved cannot be of any help. They tend to shy away from ignorance of what to say to help. Examples of a socially unspeakable loss would be: an overdose of morphine, a murder, a suicide.
- Geographic distance from social support: In this instance the individual is either away from his/her social supports at the time of mourning or there are no existing social supports available to assist the person. Geographic distance from support is becoming more and more apparent as people are becoming increasingly mobile. In addition, deaths may occur in places or at times when individuals may be unable to travel conveniently or quickly. The difficulties inherent in this type of situation are seen in the dilemma of the twenty year old college girl whose mother did not tell her that her father had died until after she returned from school when her final examinations were over. By that time the family had already dealt with a great deal of their own grief and provided little support to the daughter in her own grief. Additionally, some individuals have no social supports in the first place. Reasons for this include the breakdown of the nuclear family; a decline in primary group interactions with consequent depersonalization and alienation; and the diminished importance of religious institutions,

all of which were sources of support for the individual in the past.

- Assuming the role of the strong one: In some situations there are certain individuals who are designated to be the "strong one" by those around them, i.e., they must make all the funeral arrangements, etc. Often these individuals miss the opportunity to deal with their own grief due to the role they try to maintain.

- Uncertainty over the loss: In cases where the loss is uncertain, e.g., a boater lost at sea, a child who is kidnapped, the grievers and their social systems are often unable to commence grieving until they know the status of the lost person. This is why so much money and time is spent searching to recover missing bodies and confirm the death.

### Psychological Factors Influencing Failure to Grieve and Abnormal Grief

- Ambivalence and guilt towards the lost person: Unresolved grief may occur when the individual has profoundly ambivalent feelings toward the deceased. They may result in the individual's being frightened to grieve for fear of discovering negative and unacceptable feelings. The recognition of such feelings may prompt feelings of guilt in the mourner. Some individuals cannot complete their grief work because they would have to review their relationship with the deceased and they may be reluctant to do this if they feel guilty about some of their actions or feelings related to this relationship, either now or in the past.

- Loss of an extension of self: An individual may be so dependent upon, or place such a high value on the deceased, that he/she will not grieve in order to avoid the reality of the loss. One patient said, "Mother was my other half. I cannot be complete without her. She cannot be dead."

- Reawakening of an old loss: Some individuals are reluctant to grieve because the current loss reawakens a more profound and painful loss that has not yet been confronted. An example of this would be the man who cannot grieve for his divorce because it resurrects the memory of the death of his mother for whom he never appropriately grieved.

- Overwhelmed by multiple loss: Some people who experience multiple losses such as the death of an entire family, or who suffer a number of losses within a relatively short period of time, have difficulty grieving because the losses are too overwhelming to contemplate and deal with in the grief work. In the case of losing one's family members, it is additionally complicated because the family, who would normally support the grief, no longer exists.
- The need to be strong and in control (and other idiosyncratic resistances to mourning): Some individuals do not permit themselves to grieve for fear of losing control or appearing weak to themselves and others. For example, some people have expressed the concern that if they start to cry the tears will never stop. Others are afraid to give up the pain since it binds them closely to the deceased. There may be numerous other idiosyncratic resistances which have to be interpreted by a therapist if not worked through by the individual.

## Symptoms and Behaviors of Unresolved Grief

The following list (adapted from Lazare, 1979) enumerates some symptoms and behaviors indicative of unresolved or abnormal grief. Combined with those noted by Lindemann in 1944 (see above), they delineate the major evidences of grief work that is incomplete if they are manifest beyond the normal time expected for such symptoms to subside. It is very important to note that this determination of abnormal grief is a very relative matter, depending on the type of loss and the psychological, physiological and social factors influencing the griever's response. Usually as long as a grieving behavior is not physically or psychosocially dysfunctional, harmful, or representative of pathology of a more severe nature, then it can be viewed as "non-abnormal" and seen as part of the defensive process of grief. This allows for a wide variety of reactions in which the typical, but by no means exclusive, guideline for duration is usually six to twelve months for the very intense symptoms. It may, however, take much longer, sometimes up to three years, for the less intense symptoms to diminish. The more of these symptoms listed below that the patient evidences, the stronger the diagnosis of unresolved grief.

- The development of a depressive syndrome of varying degrees of severity following a subsequent loss which alerts one to the possibility that the prior loss was never adequately resolved
- A history of delayed or prolonged grief which serves to indicate that the individual characteristically tends to avoid or have difficulty with grief work
- The appearance of symptoms of guilt, self-reproach, panic attacks and somatic expressions of fear such as choking sensations and breathing attacks
- The appearance of somatic symptoms representing identification with the deceased, often the symptoms of the terminal illness
- The experience of distress under the upper half of the sternum accompanied by expressions such as "something stuck inside
- Continuation of the searching behavior. Searching is a normal component of grief as the individual seeks to find and reunite with the lost loved one in some form. In this instance, the searching behavior continues unabated as there is exhibited a great deal of scattered behavior and physical moving around
- Recurrence of depressive symptoms and searching behavior on specific dates, anniversaries and holidays. Although anniversary reactions are common, it is the intensity and type of symptoms which demarcates this from the normal anniversary reaction
- Feeling that the death occurred yesterday even though it occurred long ago. This is also the feeling that is conveyed to the listener when the bereaved is speaking of the loss
- Unwillingness to move the material possessions of the deceased after a reasonable amount of time has passed
- Diminished participation in religious activities
- Recurrent themes of loss in an interview with the bereaved
- If the loss is over one or two years old and the individual cannot discuss it with equanimity

- When relationships with friends and relatives shifts for the worse
- When the person avoids visiting the grave or participating in rituals that are part of that individual's culture
- When the individual fails to grieve initially following the loss

## Mortality and Morbidity Following a Death

There have been a number of investigations that have illustrated the possible physical sequelae of a loss through death (most notably Lindemann, 1944; Parkes, 1964, 1970, 1972, 1973; Rees and Lutkins, 1967; Maddison and Viola, 1968; Glick, Weiss, and Parkes, 1974). All of these have concluded that the death of a loved one carries with it a definite physical risk much greater than would be expected in the normal population. For example, Parkes (1964) found that within a six month period following the death of their husbands a group of London widows under sixty-five had tripled their psychiatric consultation rates and had sedation prescribed for them at seven times the amount prior to the death of their husbands. Maddison (1971) found that thirty-two percent of bereaved widows suffered a marked deterioration in health thirteen months following bereavement as compared to only two percent of a control group. Glick, Weiss, and Parkes (1974) discovered that within eight weeks after the death of their husbands forty percent of the widows they studied had consulted their physicians because of headaches, dizziness, sleeplessness and loss of appetite. Parkes (1973) reported that this same population spent considerably more time in bed than did the control group and had three times as many hospitalizations in the year following bereavement.

Mortality statistics have been researched and there is a strong mortality risk to the bereaved. Kraus and Lilienfeld (1959) and Parkes, Benjamin and Fitzgerald (1969) found an increase in mortality rates of forty percent for widowers in the first six months subsequent to the loss. Studies by Cox and Ford (1964) and Rees and Lutkins (1967) also found a significant increase in mortality for the bereaved as compared to the control populations.

These studies corroborate a wealth of clinical description that reveals the state of bereavement to be one of great psychiatric and physical risk. For these reasons the importance of adequate resolution of the grief work cannot be stressed too much.

## How to Help the Griever

What the griever needs most is to be allowed the acceptance and non-judgmental listening which will facilitate the expression of grief emotions and the necessary reviewing of the relationship with the lost loved one.

In his excellent book, "Understanding Grief," Jackson (1957) notes that the goal of the therapist (or any consoler) is to assist the individual in releasing the emotional ties to the deceased despite the attending discomfort and sorrow, and to subsequently replace the type of interaction lost. The individual must be persuaded to yield constructively to the process of grief and this involves acceptance of the discomfort generated by looking realistically at the loss. The griever is encouraged to participate actively in the work of mourning instead of trying to escape or deny it, and to realize that the grieving period can be delayed but not postponed indefinitely, for it will be carried on directly or indirectly.

Lindemann (1944) delineated how the individual must confront his loss and grief:

> ...comfort alone does not provide adequate assistance in the patient's grief work. He has to review his relationships with the deceased and has to become acquainted with the alterations in his own modes of emotional reaction. His fear of insanity and his fear of accepting the surprising changes in his feelings, especially the overflow of hostility, have to be worked through. He will have to express his sorrow and sense of loss. He will have to find an acceptable formulation of his future relationship to the deceased. He will have to verbalize his feelings of guilt, and he will have to find persons around him whom he can use as 'primers' for the acquisition of new patterns of conduct.

Important ways in which a therapist or consoler can assist the griever in appropriately and adequately confronting his loss are to:

- Be present physically, as well as emotionally, to render the griever security and support. This is especially important during the initial period of shock and disorganization in which consistent physical presence and physical contact (e.g., hugging, handholding) not only conveys to the griever that she/he is not alone, but helps re-orient the griever to the world that has gone out of focus and control with the loss of the loved one. Naturally such physical support is important throughout the entire mourning period. However, it becomes crucial again at the time when the true implications and reality of the loss sinks in, weeks and months after the death. This is the time when most social support has dwindled as people assume the bereaved is "well over it" and they diminish their interventions. For many grievers this period of time is actually the most difficult, as the pain of loss is felt most acutely with the griever being forced to resume life without the loved one.

Especially during the early periods of shock and disorganization it may be helpful for someone to take charge of some of the routine functions and responsibilities of the bereaved (e.g., providing meals, doing errands, etc.). During this time it may be therapeutic to render the security of some direction, as the bereaved may be unable to provide their own.

- Assist the griever in accepting, expressing and identifying feelings
- Listen non-judgmentally and with permissiveness and acceptance so the griever can ventilate emotions without fear of rejection. This is important since many of the emotions of grief are unacceptable and guilt-provoking to the mourner and yet they need to be expressed. As Shakespeare wrote, it is important to give words to grief and sorrow, for when a passion can expend itself in words it is less apt to result in deeds: "Give sorrow words; the grief that does not speak whispers the o'er-fraught heart, and bids it break." Unless the mourner can feel accepted, this very necessary therapeutic process will be thwarted.

It will be important for the bereaved to cry and cry, talk and talk, review and review without the interruptions of our sanity. These processes are crucial in enabling the bereaved to effectively complete the requisite grief work.

- *Let your genuine concern and caring show*
- *Encourage the griever to talk about the deceased*. Encourage the discussion of the negative as well as the positive aspects of the deceased and their mutual relationship
- *Provide the griever with normative data about the grief process* to alleviate concerns about "I'm going crazy" and facilitate appropriate grief work (e.g., explain that a certain amount of ambivalence is normal in all relationships). Essentially one tries to "normalize" the person's grief. This is consistent with Fulton's (1967) two principles for assistance to bereaved children, which also applies to adults: (1) prevent distorted grief responses; (2) facilitate normal grief processes
- *Encourage the griever to be patient* with him/herself, and *not to expect too much* of him/herself, *and not to impose any "shoulds"* on him/herself

There are a number of things *not* to do:

- Do *not* support flight, e.g., through moving, taking a vacation, making significant changes, etc. If this occurs too early the bereaved will find they are stripped of their stable roots and the security of familiar surroundings
- Do *not* allow the griever to remain isolated
- Do *not* let your own sense of helplessness keep you from reaching out to the griever
- Do *not* encourage responses antithetical to appropriate grief. For example, do not say "don't cry," censor the person's anger or guilt, or tell the person to take a tranquilizer just to avoid some somatic distress
- Do *not* be afraid to mention the dead person to the griever
- Do *not* be amazed if the griever talks about many of the same things repeatedly. Grievers need to review and review the relationship with and memories of the deceased

- Do not let your own needs determine the experience for the griever. For example, do not close down a conversation about the deceased because it hurts you to see the griever cry
- Do not expect the bereaved to be exactly the same person after the loss. The experience of loss will change the bereaved to a greater or lesser extent, both positively and/or negatively
- Do not tell the griever they should feel better because they have other loved ones who are still alive. This robs them of their legitimate sadness
- Do not try to explain the loss in religious or philosophical terms too early; e.g., to say "it's God's will" will not be helpful when grievers need to ventilate their anguish and feelings. Such explanations may be helpful later on in assisting the griever to find some meaning and/or perspective in their loss
- Do not push grievers into new relationships before they are ready

Obviously all of these suggestions hold true within certain limitations. Grief which is absent, distorted, too prolonged or intense will need confrontation by professionals. There will be times, too, when the consoler will need to become more directive and assertive with the griever. For although the bereaved require non-judgmental acceptance and support, there will be occasions after a period of time when they could benefit from a gentle, loving and well-timed nudge in the direction toward meeting the three goals of appropriate grief work.

## Duration and Resolution of Grief

The duration of grief is variable and will depend upon the influencing factors of the grief response (see previous sections "Factors Influencing the Grief Reaction"). Obviously these factors will also determine the extent and type of grief experience. The research that has been conducted on the duration of grief is scant, inconclusive and is artificially biased since the follow-up period is usually only eighteen months, precluding knowledge of what happens after this time period. This prohibits making a valid, generalized statement about the length of normal grief. As stated previously, a rule of thumb is that as long as a grieving behavior is not dysfunctional (physically or psychosocially), harmful, or representative of pathology of a more severe nature, then it can be viewed as "not abnormal" and seen as part of the defense process of grief. This allows for a wide variety of reactions and fluctuating intensities of bereavement symptomatology. Although we once thought that the symptoms of grief lasted only six months, we now talk in terms of years. Symptoms of grief may take up to three years to be "resolved," although the saying "once bereaved, always bereaved" is most definitely true. There are some parts of the loss that will be with one until they die. Most of the more intense reactions of grief, however, usually subside within six to twelve months. Yet, it must be stressed repeatedly that no evaluation can be made about grief and its duration unless one takes into account all of the psychological, physiological and social factors which influence a specific grief response (or the lack of it) to a specific loss.

Anniversary reactions are to be expected. These are brief upsurges in grief which occur during certain times of the year (e.g., during anniversaries of important events, holidays, birthdays) or to certain stimuli (e.g., special song, photograph, special location) and are normal within limits.

Lazare (1979) has delineated some criteria suggestive of the resumption of one's life with successful resolution of grief. As with most other aspects of grief, these will be evidenced in a waxing and waning fashion:

- The depressive symptomatology of bereavement disappears
- The individual's time sense goes back to normal, i.e., they can let time go on now
- There is a different kind of sadness, i.e., from a bitter sadness there is a change to a sweet sadness
- The individual displays more equanimity when discussing the loss
- The individual starts to be able to enjoy holidays
- The "searching" for the lost loved one ceases
- The individual relates better to others
- There is a more therapeutic relationship with the deceased

## Wakes, Funerals, and Other Mourning Rituals

Mourning rituals provide some structure and norms for the bereaved in their grief. They provide an opportunity for survivors to express their love, respect and grief for the loved one who has died. In this respect funerals are quite important psychologically. Although an individual may disagree with the tendency of Americans to foster ostentatious or death-denying wakes and funerals, their purposes and functions are quite important.

There have been funerals since the time of prehistoric civilization. All cultures have some ritualized form of body disposition and rite of passage. Basically there are three purposes of a funeral rite:

- They mark the transition between life and death and validate that the individual had existed
- They provide an occasion and location for other individuals to offer support to the grievers
- They provide for disposition of the body or remains

The wake (or Shivah, for those in the Jewish religion) facilitates several needs of the grievers. First, it assists in the confirmation of the reality of the death. The natural urge to want to deny the death is confronted by the ceremony of leave-taking. Viewing the body is often quite helpful in that it reverses the process of denial while promoting acceptance of the death and confirming its reality. It also provides a meaningful symbol upon which to focus attention and which can stimulate emotions and memories which need to be ventilated, as well as providing the climate for mourning and expression of feelings. Thus, the three purposes for viewing the body are: realization of the fact the death has indeed occurred, recalling the memories and feelings toward the deceased, and prompting the expression of these memories and feelings.

The wake or Shivah also provides the setting for the social support of the bereaved that is so crucial. It affirms to the bereaved that they are not alone in their grief. Additionally, it facilitates the expression of feelings on the part of the bereaved as well as of the consolers.

Therefore, the basic purposes of mourning rituals are quite therapeutic in nature. If the rituals have become less than that, the error is in the interpretation, not the design.

## Grief and Children

The majority of that which describes and defines adults in grief also holds true for children. Like adults, children will display a variety of reactions to the death of a loved one. They go through the same types of grief and have many of the same needs as adult grievers.

What differences there are between grief in adults and grief in children are usually the results of the differences in the child's cognitive grasp of death (see following submodule "Death Across the Life Cycle") and the results of the manner in which the information about death has been conveyed to them by adults. Many of a child's problems with death and grief arise from the poor ways in which adults interact with children around the topic of death.

For example, children are often told myths or fairy tales about death instead of the truth. Grollman (1974) discusses some of these in light of the unexpected detrimental effects they can have upon children.

Example 1: "Mother has gone on a long trip"

Child's Reaction:

- Anger and resentment ("Why didn't she take me?" "Why did she leave?")
- Feelings of abandonment and guilt ("I must have done something bad to make her leave me.")
- Delusion that Mother will return
- Wonder at why everyone else is so sad and crying

Example 2: "God took Daddy when he was so young because your father was so good that He wanted your father for Himself."

Child's Reaction:

- Resentment and anger against God ("I needed him")
- Fear of being good ("I might be taken")

Example 3: "Grandma died because she was so sick."

Child's Reaction:

- Associates all sickness with death

Example 4: "Your aunt died. Now she's sleeping forever."

Child's Reaction:

- Associates sleep with death and becomes afraid to go to sleep

There are several important things to remember when telling a child of the death of a loved one.

- The child should be told immediately in order to prevent hearing it from someone else
- The child should be told by a close person, preferably in familiar surroundings
- The child should be given as honest an explanation as possible within his limits of understanding. (e.g., Children who are very young will not be able to understand the notions of irreversibility and permanence but they can, for example, understand something like the analogy of death as being similar to a broken toy (something which the child can definitely comprehend): in both, that which is loved does not function anymore, and although you would like to get it fixed it cannot work again... etc.)
- Convey to the child that he/she is loved and will continue to be taken care of even though a very sad thing has happened and the adults are very upset. It is frightening for the child to see adults upset, but this must not be hidden since it is a natural reaction and children need to know that it is permissable and normal to express grief. It should be explained as such and should accompany attempts at making the child feel secure even though there is a great deal of change occurring
- Predict for the child that he/she may feel sad and have strange or different feelings for awhile. Let him know that this is natural and that they should talk about those feelings. Convey that such feelings will not last forever. Often the child is not included in funerals and other rituals of mourning. Often children are sheltered from the grief expressions of adults. CHILDREN HAVE A RIGHT AND A NEED TO BE INCLUDED. They should be allowed to share their grief with those they

> love. Silence about the death and isolation from significant others at this time deprives children from the opportunity to deal with their emotions. In addition, if children are not included, they start to feel insecure and abandoned as they see adults reacting and sharing in an experience in which they cannot share. Thus, children are shut out at the time they most need to be included. This does not serve to protect a child, but only to harm

The child should be given the opportunity to decide whether to go to the funeral or not. Never force a child to go. If children decide not to go, respect that and let them know they can visit the grave or the church when they want to and that you will be with them if they want. If the child decides to go, explain the details in advance so that the child will have some idea of what to expect.

Frequently, adults project their own fears and concerns onto children and for this reason assume that the funeral will be devastating to them. It definitely need not be. Of course it will be sad, but it is always sad to lose one whom we love. Since we try to prepare our children for dealing with life in the real world, we must also try to prepare them for the losses and deaths which they inevitably will confront. It is so much better if we can be the ones to help children face the sadness of grief when we are there to assist them in the coping with it. The alternative is to try to hide children from the real world and perhaps have them have to confront its griefs when we are not there to help.

It will be important to watch out for the childish association leading to the idea that their personal wishes or actions caused the death of their loved one. This may also be observed on the adult level but is especially prevalent in children due to their "magical thinking," e.g., the child who feels responsible and guilty for the father's death because he had engaged in a fight with him or had said "Drop dead!" These misconceptions must definitely be corrected. Additionally, it will be important for adults not to evaluate the child's grief solely in comparison with the adult's (although there are more similarities than differences). Sometimes children will not react at all to the news that a loved one has died. Sometimes they appear to be little disturbed and will want to continue to play instead of attending the funeral. We may feel that they are insensitive to the death or that they do not understand it. This conclusion may be quite incorrect. Children engage in denial just as adults, and the behaviors observed may be the more primitive manifestations of the same denial of the adult. The most therapeutic posture in situations like these are to let the children know that you will be willing to discuss the death and their feelings when they are ready.

In summary, it is necessary that adults discuss death with children in order to demystify it. Ideally, prior to the loss of any loved one, the child will have had some conversation with an adult about death and its natural part in the course of life. Adults can utilize the numerous "teachable moments" that constantly occur in everyday life to instruct their children about death and grief. For example, the death of a pet or a national personality can provide a natural opportunity for adults to discuss death and its implications/ramifications with their children. In this way, when death occurs to someone in the child's life, the child will not be totally unfamiliar with it. (This is a prime indication for the need of and reason for the importance of Death Education in the schools and homes). A death should not be hidden from children for they will be able to sense something is wrong and will feel the worse for being excluded. Do not be afraid of letting children see you grieve as long as you continue to make them feel loved and secure. After all, death is sad and painful, but sadness and pain are part of life and children have to learn to live with it. It is better that they learn in the security of a close family environment.

## C. THE DYING PATIENT*

### Death As A Crisis Situation

The diagnosis of a terminal illness presents the individual with the information that life, as that individual has known it, has a limited future. Such limitation demands accommodation and reorientation in living, values, goals and beliefs

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*This submodule is written on the adult dying patient. The unique issues of the terminally ill child are not within the scope of this writing, outside of the information presented in the submodule "Death Across the Life Cycle." For more complete discussion the reader is referred to Schowalter (1970), Spinetta (1974), Easson (1970), Martinson (1978), Gyulay (1978), and Bluebond-Langner (1978).

From late childhood individuals are cognitively aware of the universality of death, and, by implication, of the fact that they too must die one day. Yet, the news that one has contracted a life-threatening illness and will die as a result of it, although conveying nothing fundamentally new (since it is expected we will all die), does alter the individual's perspective radically. Previously, the fact of personal death could always be denied. It was some event in the future which could easily be repressed and sublimated. Now, after being told that one is terminally ill, the individual is compelled to take a good hard look at impending death and the meaning it has in the person's life. One cannot avoid confronting it anymore.

Parad (1965) analyzes the crisis of the knowledge of death within the five aspects of crisis (as adapted from Pattison, 1977).

- This stressful event poses a problem that by definition is insolvable in the immediate future. In this sense, dying is the most stressful crisis because it is a crisis to which we can only surrender and cannot solve
- The problem taxes one's psychological resources since it is beyond one's traditional problem-solving methods. One is faced with a new experience with no prior experience to fall back upon, nor can one get such experience second-hand. Although one has lived amidst death, it is far different from one's own death
- The situation is perceived as a threat or danger to life goals of the person. Dying interrupts a person in the midst of life, and even in old age it abruptly confronts one with the goals one sets in life
- The crisis period is characterized by a tension which mounts to a peak, then falls. As one faces the crisis of death anxiety begins to mount, then rises to a peak during which the person either mobilizes coping mechanisms or experiences disorganization and capitulation to anxiety. In either case, one passes to a state of diminishing anxiety as one approaches death. The high point for the anxiety usually occurs considerably in advance of death
- The crisis situation awakens unresolved key problems from both the near and distant past. Problems of passivity, dependency, narcissism,

identity, for example, may be activated during the dying process. Hence, one is faced not only with the immediate dying process but also with the unresolved feelings from one's own lifetime and its inevitable conflicts

There are three commonalities of facing death. These are: the feeling of limit, wherein the individuals feel trapped in illness; the feeling of loss, where the individuals recognize that they must necessarily lose all that they have ever known here on earth; and the feeling of change, where the individual becomes dependent on others around them (Gordon, 1970).

The individual will struggle to cope with the crisis of the knowledge of impending death and these common feelings arising from it. However, psychological defense is difficult for the terminally ill patients for the following three reasons (Verwoerdt, 1966):

- The illness itself and the physical sequelae of it deplete the ego of energy required to maintain appropriate defense and coping mechanisms
- The individual has had no previous experience with death to assist in the adaptation to it
- Healthy adaptation requires the expectation of pleasurable results in the future. This is absent in the patient facing a terminal illness

For these three reasons, the stress of the knowledge of fatal illness severely taxes the coping abilities and defense mechanisms of the individual's ego. This is why the crisis of the knowledge of death is such an overwhelming one to face.

There are various ways in which patients may react to the news of terminal illness. They may accept or deny the news, vascillate between accepting or denying, or do both simultaneously. They may overtly express knowlege that they are dying, but emotionally be unable to accept it. Conversely, they may accept it, but be unable to verbalize it (Kalish, 1970). Patients may react as they have to all past crises or they may respond with a slight change in personality. They may become narcissistic and demanding just to insure they will not be left alone. They could use reaction-formation or excessive denial and stoicism. They could become somewhat paranoid and need someone upon whom to blame all their problems. Whatever the response, it is undertaken to serve the needs of the patient at that moment.

Koestenbaum (1972) delineated a number of the implications inherent in being informed that one is terminally ill. Among the most salient are:

- The patient may feel shock and numbness, but submitting to these feelings will not change the situation
- The patient is then forced to decide exactly what is and is not important in life
- The patient is compelled to face the question of the ultimate meaning of his/her life. The patient must be honest and not procrastinate
- The patient becomes aware of the limits of life
- The patient sees the present moment in relation to death. Life unfolds itself in the direction of death. The patient should realize that all life points to death
- For the patient, what may have seemed depressing, frustrating, and hopeless before, now achieves meaning

Therefore, the manner in which a patient reacts to the news of terminal illness is contingent upon a number of factors. To understand and effectively appreciate the patient's reactions one must view them in the spectrum of the patient and the patient's personality and experiences as a whole.

## Tasks of the Dying Patient

As patients strive to cope with the threat of impending death they also undertake a variety of additional tasks. Most, if not all, of these tasks only serve to remind the patient even more acutely that time on earth is limited. It is important that those close to the terminally ill patient recognize this and assist in any possible manner with the executing of these tasks. As outlined by Kalish (1970) the tasks are:

- The patient must contemplate arranging a variety of affairs. Each one signals impending death. Each one brings the patient one step closer to it. These include: getting the will in order; paying back debts;

checking on insurance policies; leaving messages for friends, neighbors, and co-workers; making funeral and burial arrangements; and taking care of the welfare of those left behind. Often pain and discomfort, fear, anxiety, confusion or disability hinder the patient from taking a direct role in these arrangements. If denial has caused the patient to reject the notion of immediate death, such arrangements may not be made at all

- The patient must undertake the task of coping with loss, both of loved ones and the self. Dying persons are often deeply concerned with what effect their death will have upon their survivors in ways other than legal and financial. They will frequently consider their survivors' grief, their needs, their vulnerability, their coming need to establish replacement relationships, etc. All of these feelings may be discussed and have a potential for bringing patients and their loved ones closer if the feelings can be openly and honestly discussed. Mutual pretense precludes any such interaction and the deceit wears emotionally on all those involved and robs them of meaningful interaction at this time. Similarly, the dying patient must accommodate the self to its own loss. The patient is going to lose the entire known world and all of the people in it. Coping with this impending loss is one of the most difficult tasks for the dying person whose tears are a combination of the reaction to the loss of self and empathy with the sorrow of loved ones

- The third task of the dying patient is to see to future medical care needs. Often this task can be left to others, but many times the patient derives a sense of satisfaction in exercising some control in such matters as location of death and use of analgesics, etc.

- Another task is that of planning the future and allocating whatever time, energy, and financial resources may be left to the patient

- Patients also have to prepare themselves to anticipate possible future pain and discomfort or face possible loss of various forms of sensory, motor, or cognitive abilities. It often turns out that the realities of the situation are less important than the anticipation of them. Changes in appearance and loss of performance and function must be reckoned with. All of these prospects are extremely anxiety-provoking to the patient

- "The loss of physical function, the fear of regression, the recognition of loss of control over physical and cognitive capacities, the coming destruction of the body; all these suggest a loss of self or a loss of identity" (Kalish, 1970, p. 64). The question arises of what will happen after the body ceases to exist. Who or what is the patient then? Just a statistic? A memory? A name in the record books?

Thus, the sixth task is that the patient copes effectively with the death encounter and similarly with the feelings of loss of self and identity. The patient must consider being a non-person, a forgotten person, a person whose continuation resides only in memories, pictures, and temporary results of work and human relationships. The patient must cope with the fear of a rite of passage from which no one has returned with descriptions of the new role. The patient has to cope with the possibility of permanent extinction.

This coping with the death encounter inevitably brings up concerns of immortality. Many are comforted through their religion at this time. Others, while religious, find no such comfort. The research on the role of religion has produced mixed results. Whatever the beliefs along these lines, the consideration of immortality is usually elicited with the imminence of death. Living memories may be hoped for in one's children, artistic, or industrial contributions. It is at this time that patients who do not feel fulfilled, or as though they have contributed to society, will sink into what Erikson has termed the state of despair. (1950)

- This task is one in which the patient makes a decision, to whatever extent that it is within the power of the self to speed up or slow down the dying process. If patients feel that, in dependency, they are an emotional and financial burden on the family, or if they feel guilty in their nonproductive status in society, they may wish to stop fighting and may give up the will to live. This is something that each patient has to decide for him/herself, if indeed she/he can still make that decision

## Types of Death

There are four types of death that each dying individual actually undergoes: social death, psychological death, biological death and physiological death. Ideally these four types of death follow in the above order and facilitate one another.

Social death represents the symbolic death of the patient in the world the patient has known. Socially, this world begins to shrink. This occurs naturally when the individual is hospitalized and removed from the familiar environment. The number of social contacts diminish accordingly. Withdrawal and separation from people in the patient's environment result from an increasing preoccupation with the illness and grieving for the losses to come. Usually, by the end of the illness, contacts are limited to only the several of those significant others who are closest to the patient.

In some cases, however, social death occurs much earlier than necessary. In these situations, individuals may be deserted and placed in nursing homes by families who already consider them as dead. Or, they may be placed at the end of the hospital floor in order not to provoke anxiety in the hospital staff who are made uncomfortable by a dying patient. Studies have been done which illustrate that the needs of the terminally ill tend to be met much less efficiently than do those of the acutely ill. One classic study noted how nurses took longer to respond to the call lights of terminally ill patients than to those of the acutely ill. All of this reflects the discomfort that the dying provoke in those around them. Although such anxiety is understandable, it needs to be managed in ways that are therapeutic and not deleterious to the patient. Social death is a natural part of the dying process but care must be exercised to insure that it derives from the natural sequence of the patient's dying trajectory and not from the defensiveness of those in close proximity.

Psychological death refers to the death of aspects of the dying individual's personality. Terminal illness demands some degree of regression and dependency just in the fact that the individual is no longer capable of the same degree of autonomous functioning as previously. Additionally, grief over the losses (symbolic and physical) resulting from the illness contribute to personality changes, as does the patient's pain and the decreasing interest in the external world resulting when the dying individual decathects from the world and many of the people in it. Dying individuals start to regress and draw into themselves. The disease process itself often fosters personality changes biochemically, as do medication and pain. In essence, the individual, as others know that person, dies.

Biological death refers to death in which the organism, as a human entity, no longer exists. There may be artificial support which keeps certain organs functioning, but the human traits of consciousness and awareness in a self-sustaining mind-body organism are dead.

Physiological death occurs when there is a cessation of the operation of all vital organs.

Ideally, these four types of death succeed one another in relatively orderly fashion. Social death paves the way for psychological death. Therapeutic intervention would attempt to structure the environment so that these two types of death do not occur too far in advance of the latter two. When biological death precedes physiological death by too great an interval, crucial questions of bio-ethical concern arise as evidenced in such legal-moral issues as euthanasia, transplantation, and "pulling the plug."

Obviously, the goal of Hospice would be to create the climate for all four types of death to occur as coincidentally as possible.

## The Anticipatory Grieving of the Dying Patient

In the previous section, "Grief: The Reaction to Loss," the psychological, physiological and social reactions to loss are discussed. In many ways, the grief processes of the dying individual parallel those of the bereaved individual. In this sense, the grief of the person with a terminal illness is akin to the anticipatory grief discussed previously. In anticipation of a multitude of future losses, the individual grieves. Such future losses include not only the demise of the self but also:

- Loss of control
- Loss of independence
- Loss of various psychological, physical, and cognitive capacities and functions

- Loss of significant others, external objects and familiar environment
- Loss of some aspects of the self and one's identity (including the feelings that one has had about the self and its attributes, e.g., competent, lovable, attractive, worthy, etc.)
- Loss of meaning, and the loss of the world and relationships to the people in it

*Although the dynamics of the anticipatory grief of the terminally ill have much in common with the previously discussed grief of the bereaved, there are some significant differences*. These differences are in the matters of endpoint, acceleration, hope and the vulnerability to ambivalence (Aldrich, 1974).

In terms of endpoint, the grief of the bereaved subsequent to a loss can be indefinitely prolonged. In contrast, the grief of the dying patient has a *finite endpoint* dependent upon the occurrence of the death. Under ordinary circumstances, the grief of the bereaved decelerates as time passes. Theoretically, anticipatory grief should increase as the anticipated loss becomes more imminent. However, defenses mobilized to cope with the stress, especially denial, may so influence the anticipatory grief as to result in the clinical observation that overt grief in anticipation of loss does not accelerate consistently in degree as the loss approaches as theory would dictate. Both the direction of and the rate of change in the extent of grief will be affected by individual factors.

The differences between anticipatory grief and post-death grief in terms of *hope* are found in the reality that prior to the loss there can always exist some possibility of hope and the opportunity to take some action which could conceivably delay the loss or prevent it from happening. In post-death grief whatever measures the mourner takes cannot affect the timing or extent of the loss. The mourner cannot alter the irrevocable fact that the loss has occurred.

*Ambivalence* has a special impact upon anticipatory grief, especially with respect to the likelihood of denial. The terminally ill patient often struggles with ambivalent feelings over the fact that it is she/he, and not other loved ones, who is going to die. Feelings of anger and jealousy, along with a sense of being cheated, contribute to this ambivalence. Consequently, there may be an increase in the denial of potential losses as the dying patient tries to cope with negative feelings which are often quite unacceptable to him/herself. Ambivalence may also be present for the bereaved after a death, but the unique situation of terminally ill anticipatory grievers tends to make them more vulnerable to it, as well as vulnerable because of it, i.e., since they do not want to alienate others with their negative feelings and end up being left alone.

Therefore, the dying individual struggles with the same tasks as the mourner after a death (see previous section). Obviously, there will not be a period of reestablishment per se, but for many terminally ill persons this is replaced by the state of realization or resolution (to be discussed below). Other differences may be found in the intensity of some of the emotional reactions described below. Although they are also concommitants of normal post-death grief, these reactions are particularly salient for the individual mourning the loss of self through imminent death.

## Emotional Reactions and Fears of the Dying Patient

### 1) Anxiety

Anxiety is composed of apprehension and occurs in the absence of a specific danger. It differs from fear in that it is non-directed in nature. In fear, the individual recognizes the threat. In anxiety the individual frequently cannot specify what it is that is causing him to feel anxious. Some degree of existential or annihilation anxiety will be common for anyone contemplating their own death. It is a natural reaction.

One of the ways in which a dying individual's anxiety can be made more manageable is to assist them in specifying those particular issues in dying that may contribute most strongly to their anxiety in order that these can be addressed individually. An accurate assessment of the patient's specific concerns is necessary in order to therapeutically meet his/her particular needs and fears thereby reducing the anxiety by delineating its components and responding to what causes it. Essentially the anxiety is broken down into its more manageable fears so that the patient can cope with the specific fears instead of the more global (and thus more terrifying) generalized anxiety.

It is important to note that although most individuals are afraid of and anxious about their own deaths, it is not the same issues which are difficult for all persons. In other words, each individual will have specific fears about death. What is of the utmost concern to one person may be negligible to another. Pattison (1977) delineates a number of fears or part-aspects of the experience of dying. He notes that although we cannot conquer the ultimate problem of death, we can help the terminally ill person to cope with the various parts of the process of dying. He believes that by focusing on these part-aspects the crisis can be made more manageable for patients and thus enable them to cope more efficiently, thereby enhancing self-esteem, dignity and integrity, which are easily compromised in the attempt to confront the global issue of death, a most anxiety-provoking endeavor.

The following fears or part-aspects of the experience of dying will not be equally important to each individual. Each person will respond to the fears in a unique manner determined by such things as personality, previous experience, coping and defense mechanisms, amount and kind of support, etc. The therapeutic goals are to ascertain which fears concern the patient (almost like conducting a differential diagnosis), to assist the patient in confronting his/her pertinent fears, and to separate each issue (since one cannot deal with all of them simultaneously) so that resolution, in appropriate fashion, can begin.

The specific fears (many of them adapted from Pattison, 1977, 1966) include:

- The fear of the unknown: This fear is a strong and basic one in all human beings. That which is unfamiliar or which we cannot anticipate frightens us at all levels. From the child afraid of the dark to the adult confronting death, we all cling to the security of the familiar. Like the rest of us, the terminally ill patient is afraid of death. This fear is exacerbated by the fact that the patient will have to confront this anxious situation in the immediate future. For the dying individual it is important to separate that which can be answered about the unknown from that which cannot be answered. Diggory and Rothman (1961) note the following questions about the unknown of death:

  What life experiences will I not be able to have?

  What is my fate in the hereafter?

What will happen to my body after death?

What will happen to my survivors?

How will my family and friends respond to my dying?

What will happen to my life plans and projects?

What changes will occur in my body?

What will be my emotional reactions?

Obviously some of these questions are answerable immediately, while others will require time in order to be answered, and still others will not be answerable on this earth. Those questions that can be answered should be answered. It is helpful for the patient to distinguish between questions about the reality of life, for which answers can be legitimately given, and those related to philosophical, religious, and speculative concerns for which only opinions, but not answers, can be given. Patients may also make plans which will insure that his/her preferences will be respected with regard to other questions. (e.g., What will happen to the body after death? In order to answer that question, the patient can make his/her own burial plans.) This will eliminate some of the unknown quantity with which the patient must cope. Anything that can do this will be therapeutic for the individual confronting this fear.

- The fear of loneliness: It is well known that when individuals are afraid or placed in uncertain situations the presence of others can be reassuring or comforting. We all derive some amount of security from others. In sickness this security is not always provided since individuals tend to be isolated when they are ill or in pain. Unfortunately, as family, friends or caregivers, we tend to want to absent ourselves from having to view such things and consequently the social world of the seriously ill person diminishes. If it is anxiety-provoking to see others ill, it is especially difficult to see them when they are dying. For this reason the dying person becomes increasingly isolated from social contacts. Not only are the dying removed from a familiar environment and hospitalized, but too often, because they want to avoid acknowledging the fact that they too will die some day, friends and relatives will remove themselves. This leaves dying persons alone and without support at the very time when they most need it: during the crisis of their own dying. As in any other crisis the individual benefits from the support and nurturance of others during that period. The deprivation of social contact, as illustrated in experiments in sensory deprivation, can foster ego-disintegration in the patient. This fear of loneliness appears to be most paramount when individuals initially face the prospect of death and fear that they will be deserted in dying. It is quite ironic that this should be one of the most widespread fears of dying individuals, and also one of the ones which can most easily be eliminated by assuring the supportive presence of loving others.

- The fear of loss of family and friends: The dying individual mourns the loss of significant others just as they will mourn after that individual dies. This grief must be worked through in order for the individual to face the permanent separation entailed in death and consequently to enable the individual to die more easily and without "unfinished business" with the people left behind. Such working through entails accepting and clarifying the ambiguous and conflicting emotions between the patient and his loved ones in an effort to achieve some acceptable resolution and to reaffirm the meaning and value of the relationships. The grieving process and "working through" is very similar to that seen in the bereaved. (See previous submodule "Grief: The Emotional Reaction to Loss.")

- The fear of loss of self-control: The patient who is progressively debilitated from a deteriorating disease worries over adequacy and dependence. These are very important issues in a culture such as ours which rewards and prizes self-reliance and independence. The terminally ill patient experiences this loss of self-control over an extended duration of time with no recourse but to become more dependent as the illness progresses. It is often a humiliating and anxious process to experience. The most therapeutic interventions will encourage and allow the patient to retain whatever control is possible (e.g., making decisions about daily tasks, etc.) in order to enhance the individual's sense of control and self-esteem from whatever self-determination is yet available. In a situation in which the person has little control, i.e., a terminal illness which is ending life, any situation or decision which can render some measure of control (however little) can help ease the frustration and sense of guilt arising from the impotency resulting from the condition.

- The fear of loss of body and disability: Because our bodies are so very much a part of our self-image the loss of body parts, disfiguration, or bodily deterioration due to illness, results not only in a loss of function, but a loss of self. This blow to our self-integrity brings shame, inadequacy, guilt feelings, accompanied by feelings of being unloved and unwanted. We need to assist dying persons in grieving the losses of body parts and body-image, along with helping them cope with subsequent disability, without incurring a loss of integrity or self-esteem. We can also provide opportunities for the dying to exercise as much physical management over their own bodies as possible.

- The fear of suffering and pain: The fear that one will die in screaming torment is a common one. Individuals can usually endure pain better if it makes sense to them and they know that after the pain there will be some relief. For the dying patient these comforts are absent. There is not the expectation of a pleasurable future subsequent to the pain as there is for the patient with post-operative pain, and there often is little rationale for why it must continue in the face of the fact that the individual must die anyway. In light of this, it is important to develop the most efficacious program of pain management possible and to involve the patient in that pain management. Additionally, such psychological variables as knowledge that the pain does not constitute punishment, will not result in the patient's being left alone or ignored, and will be explained and managed as rigorously as possible, all add to the individual's greater ability to tolerate the pain. If one has the comfort of human presence and is not isolated in his pain, the tolerance of it may be made much higher.

- The fear of loss of identity: The losses of human contact, family and friends, body structure and function, self-control and consciousness all threaten the loss of one's identity, since they all serve to affirm our identity to ourselves. At the point of dying the issue will not be that one dies, but how one dies. Faced with the threat of death and dissolution, the individual is faced with the tasks of attempting to retain self-respect, integrity, and dignity in the process of dying. There are three major mechanisms for this. The first is found in the maintenance of identity through contact with those who have been and are part of one's life. Continual contact with the familiar reaffirms to dying individuals that they are still the same people they have always been. Being treated as a living person (who also happens to be dying) rather than as one who is already dead, is helpful in this regard also. It is critical for health care personnel to continue to think of the person and not the "disease." A second mechanism is reinforcement of one's identity through the continuity of one's life in one's family, friends, work and bequeathed possessions. A third mechanism is found in the maintenance of identity through a desire for union with loved ones who have died previously or those who will die subsequently and join one. There will be reunion with one's significant others. This reunion with one's parents and progeny allows one to place the self at one point in the continuum of human relationships, at which death is merely one point in the more universal span of existence.

- The fear of sorrow: As individuals contemplate the losses they will undergo as part of the dying process there is a fear that they will be unable to tolerate the attending sorrow. Therapeutic intervention will focus on enabling the dying individual to experience the joys and pleasures that are possible, especially since all losses do not occur spontaneously. It will also seek to avoid premature sorrow which could cut off the dying person from available satisfactions by focusing solely on the anticipatory grief work. There needs to be a melding of the two: anticipatory grief and enjoyment of remaining satisfactions and accomplishments.

- The fear of regression: As the dying person grows closer to death the fear of regression becomes more salient. Previously it had been a concern about final behavior (e.g., the dying person would act foolishly or childishly, etc.), related to the fear of loss of control. Nearer to death, as there is a diminution of physical capacity and clouding of consciousness, the sense of regression, of losing concrete and hard reality, where there are no boundaries of self or others and where the senses of time and space are lost, may be frightening to the dying individual. Therapeutic intervention will assist the individual in comfortably shifting away from reality to turn inward toward the self, allowing a withdrawal and surrender to the self which accompanies the turning away from life and signals psychic death. (See section on "The Issue of Acceptance, Withdrawal and Detachment, and Hope".)
- The fears of mutilation, decomposition and premature burial: These fears are not specific to the dying process but are included here since they may arise as an issue for a dying patient. They are focused on what happens to the body after death (e.g., afraid that the body will be eaten by worms after burial), and the horrible fear that the individual could be misperceived as dead and buried while still alive (as has occurred in some famous horror stories). Individuals may sustain just one or several of these related fears. These can be addressed by having patients choose their own preferred mode of body disposition and providing appropriate information about it, as well as instructing them in the medical certainties and precautions required prior to pronunciation of death.

Summarizing the fears and part-aspects of the experience of dying, Pattison writes (1966):

> Given our interest, support, and guidance, the dying person may turn to use his available capacities to deal with the several distinct part-processes of dying. He can face death as unknown with the realization that he cannot know, and instead consider the processes of dying that he can know and deal with. He can learn to endure the inevitable degrees of separation that begin to occur if he is not

> actually deprived of human contact. He can face the loss of relatives, friends, and activities and actively mourn their loss and become reconciled to it if this grief is defined and accepted. He can tolerate the loss of self-control if it is not perceived by himself and others as a shameful experience, and if he can gain control of himself to the degree that he is able. He can retain dignity and self-respect in the face of the completion of his life cycle, gradually relinquishing the unattainable and respect himself for what he has been. Then one can place one's life in a perspective of both reunion and continuity with one's personal history and tradition. If this is accomplished, then one can move toward an acceptable regression where the self gradually returns to a state of non-self. (Pattison, 1966)

## EXERCISE III

Please list your own particular fears of the experience of dying.

In what ways do these fears influence your life?  Your work?

Which of these fears are most difficult for you to respond to in a dying patient?

Why might these particular fears be more difficult for you to respond to in a dying patient?

Please share your responses with others and see how many are similar, how many are unique.

Is there any relation between the fears listed here and the personal feelings about death discussed in Exercise I? If there is a relation, why?

______________________________________________

______________________________________________

______________________________________________

### 2) Depression

Depression is another emotional reaction experienced by the dying individual. As part of the grief of the dying patient it is a natural reaction to the perception of imminent loss. Depression is a tool which aids in the preparation of the patient for the loss of all love objects and for coming to grips with the reality of demise. This type of depression has different treatment implications for the dying patient than does a reactive depression for a loss that has already befallen. In the latter case (for example in the situation of a woman who has undergone a mastectomy), reassurance, encouragements, and attempts to cheer up the patient, in addition to supporting her undertaking her grief work for her loss, are often therapeutic. In a preparatory or anticipatory depression, there will be times when it is non-therapeutic to avoid dwelling on the imminent losses. These need to be contemplated and worked through to whatever extent is possible. This will be assisted if the patient is allowed and encouraged to express his sorrow in the manners described in the preceding sections "Helping the Griever" and the previous section on dealing with the fears of the dying patient. Similar to the psychological, physical and social symptoms of grief evidenced by the bereaved after death, will be those exhibited by the terminally ill individual undergoing preparatory and anticipatory grief and depression.

### 3) Anger and Hostility

Anger and Hostility are both experienced by the bereaved and the dying. It is perfectly reasonable that the patient be angry. She/he is being deprived of a future while so many others are allowed to live on; she/he must give up everything and everyone in life; she/he is being tortured by pain in the little amount of time remaining; and people react strangely to the patient now that they know she/he is dying. At this point in an individual's illness (usually following the initial shock, disbelief and denial, and preceded by the often unanswerable question "Why Me?") it may take very little to disturb the patient. Since there is the very natural and understandable feeling of anger at the thought that death will come soon, and since the source of this feeling cannot be extinguished, the terminally ill patient is very likely to displace these feelings on anyone and anything available. (Frequently nurses are the closest targets.) Often, too, these feelings will be used to cover up the more painful ones of grief and anxiety.

Until these feelings drain off to some extent the best therapeutic approach is to recognize that the anger and hostility are natural reactions and are also symptoms of the underlying fear of death. If they can be tolerated as such, and not reacted to with counter-hostility and anger, the patient will be able to calm down. Effective nursing interventions will seek to address the anger, hostility, grief and anxiety that is present underneath the patient's aggressive behavior. Although aggressive feelings will continue to arise at other times in the future, usually they will not evidence themselves at such an intensity. The patient needs to be allowed to express anger and hostility without judgements being made, with acceptance being given, and without being made to feel guilty. Although in some cases some gentle but firm limitations will have to be put on the patient's expression of anger (e.g., patients cannot assault the doctor who rendered the diagnosis), if the patient can release pent-up frustrations through verbalization of anger or some physical activity the level of aggression will diminish.

4) Guilt and Shame

Guilt and Shame are frequent concommitants to any illness and are especially intense when one is terminally ill. Guilt arises when one behaves contrary to one's ethical principles, when one falls short of one's self-image. It involves self-devaluation and fears of punishment.

In the state of being terminally ill, the patient may fantasize many reasons for feeling guilty. Firstly, it is not uncommon for a patient to believe that the illness is a form of retribution for past real or imagined offenses. In some cases, relieving the guilt of the patient may do more harm than good. This occurs if the patient is using guilty fantasies as a form of denial in disguise. To break this form of denial before the patient is appropriately ready to handle it could result in ruining all the feelings of hope the patient might harbor about doing something else to atone for grievances besides giving his life.

There occur other reasons why the patient might sustain feelings of guilt. Angry feelings toward others not terminally ill (including health-care personnel who have much of the anger displaced upon them) often cause patients to feel guilty about their feelings. Other emotions of envy and jealousy, so understandable given the patient's condition, also serve to produce guilt. The experiencing of the normal emotions of grief may cause some people to feel guilty, e.g., the patient who feels guilty because he "lost control" and cried.

Shame is what people feel when they are observed in a situation in which they are not living up to their self-images. Feelings of shame are not uncommon in a patient who has been forced to be dependent due to illness or who is not allowed to maintain any sense of control and, most importantly, a sense of dignity.

Individuals who are terminally ill are placed in a multitude of positions where they can feel shame from either physical or psychological deficits. Part of the patient role demands the giving up of much self-reliance, control, independence, and autonomy. These things are exceptionally valued in our culture and, when not possessed or exercised by an individual, that individual is subject to strong feelings of shame. For this reason, since the nature of illness is so shameful, it is imperative that the terminally ill patient be treated with utmost respect in this very trying situation. This ranges from making sure that the patient's privacy is respected while bathing to insuring that the patient will be consulted in as many situations as possible in which some measure of control over life can be exercised, e.g., to be given the choice of whether the backrub is given before or after medication.

## Defense Mechanisms of the Dying Patient

There are three groups of defense mechanisms used by the dying patient as they struggle to cope with the crisis of their terminality. These shall be discussed below and are adapted primarily from the work of Adrian Verwoerdt (1966). Defense mechanisms are not "bad" or "unhealthy". Too many people think they are non-therapeutic. Defense mechanisms assist an individual in in coping with stress when they are used appropriately. Everyone uses them. It is the nurse's responsibility to support those defense mechanisms which are helping the patient cope. In our society, the term "defense mechanism" has come to imply an evasive, denying or avoidance action which allows the individual to "run away". We must learn to appreciate that defense mechanisms serve an adaptive function when used appropriately. They are crucial in allowing the patient to survive in the threat of his/her imminent demise. They need not imply weakness.

## I. Defenses Aimed at Retreat from the Threat and Conservation of Energy

### 1) Regression

The psychological definition of regression is as follows: "(An) ego-defense mechanism in which the individual retreats to the use of less mature responses in attempting to cope with stress and maintain ego integrity" (Coleman, 1972, p. 772). This is essentially what happens to the patient who has to come to grips with the overwhelming stress and anxiety of impending death. For the terminally ill patient this is both necessary and therapeutic (see below).

The characteristics of regression in the terminally ill individual include: restriction of interest in the external world, egocentricity (having excessive concern with the self rather than society), dependency upon others for need gratification, an altered time sense, and a preoccupation with bodily needs (hypochondriasis).

As the structure of life becomes more restricted it leads the terminally ill patient into a personal and social setting resembling childhood. Many times nurses get disgusted with patients who act like children and indeed some do. The pressure of their own death and its resulting implications for the rest of their time here have forced these people to seek refuge and turn their backs on today to seek the yesterday where the world contained security and was a less anxious place in which to live. Dependency, egocentrism and more immature methods of coping often result.

The illness drives patients into an increasing preoccupation with self since their illness requires it and their social and physical worlds are diminishing in size. The satisfaction of basic physiological needs and the absence of pain and discomfort take precedence over social needs.

This phenomenon of regression can be therapeutically utilized when it enables the patient to relinquish some independence in order to receive treatment and can aid, as well, in assisting the patient in accepting some restrictions. It functions as an aid in implementing the nurse-patient relationship in which there necessarily will be some dependency (in some cases, almost akin to a parent-child relationship) on those personnel who are responsible for care.

However, the regression can be detrimental when patients' egocentric behaviors make them a problem to the staff and then ultimately to themselves. This occurs when the defense of regression is out of proportion to the severity of the illness.

If the patient refuses to submit to natural regressive tendencies, i.e., become less independent and relinquish some self-control, the patient becomes isolated without being able to accept the help and support of others.

An important variable of the individual's regression is an *altered* time sense. The time sequence of the regressed patient is different from that of the adult who is not terminally ill and must necessarily be so. The regressed patient's sense of time becomes as that of a child. Instead of looking forward to the future in months and years, which to the fatally ill individual is extremely anxiety-provoking since the future contains only imminent death, the patient becomes as a child and takes the future on a day-to-day basis. This relieves some of the anxiety and creates a situation in which some hope can be reactivated. The patient is protectively offered a refuge wherein the possibility of limited planning and action can be maintained. For this reason it is helpful to have patients have some little thing to do each day so that there is something to which they can look forward. This is also why doctors should try to make regularly scheduled visits to the patient.

The *egocentricity* and *hypochondriasis* of the regressed patient are closely related. Due to lack of other stimulation and the nature of the condition, the patient becomes engrossed in the physiological manifestations of the illness and eventually withdraws from many external happenings, focusing instead on the body.

Sometimes this becomes so pronounced as to make the patient a problem for physicians and nurses because of constant somatic complaints. The medical personnel may come to regard the patient as a nuisance, which is unfortunate since the recognition of such symptoms as part of an overall regressive defense constitutes one of the first steps toward effective management.

The egocentricity, however, carries with it another liability. Since the patient has reduced the scope of the world and has displayed a majority of interest in himself, the patient becomes less capable of making reliable judgements about what is happening and the ego's reality-testing function is hampered. (Although it would be wrong to assume they should not be consulted in any decision-making, it is still crucial to give them as much control as possible.) Consequently, the patient feels insecure and the need for continuous reality-testing arises. Much disturbing behavior can be interpreted as attempts to see just where the patient stands with other people.

In conclusion, it is important that the patient who is terminally ill regress to a state of dependency and to earlier modes of adaptation. A preoccupation with the self and an altered time sense, similar to that of a child's, assist the patient to sustain ego-integrity in the face of imminent death.

2) Dependence

Dependence upon others is a regressive characteristic which stems from the patient's egocentricity, disengagement, and withdrawal from previous role activities and independence. Anyone who is the victim of a chronic illness that necessitates prolonged and repeated hospitalization is inevitably placed in a position of dependency which causes the patient to feel helpless and childlike.

Reactions to these feelings can be numerous. The patient may feel guilt due to lack of independence and productivity, two attributes highly valued in our culture. The patient is often uncomfortably aware of increasing dependence upon others and may react to this with hostility and resentment, frequently cover-ups for a sense of inferiority and shame. This is obviously a very anxiety-provoking situation in which to be, since to be in the process of losing control over many aspects of one's life is to be surrendering pride and self-esteem. This is not something that the ego can take lightly.

The most effective manner of handling patients who are having difficulty surrendering their autonomy is to treat them with combinations of gentleness and firmness. Limits which are arbitrarily set, without respect for patients, never afford them any emotional calm. When limits are established and explained to patients as being for their benefit, and those limits are consistently maintained with empathic firmness, then patients feel they can be secure in the knowledge that the health-care team is looking out for the best interests of patients, not only psychologically (by treating them with respect), but also physically (by saving them from more possible pain). The analogy that best fits would be the child who feels secure because his/her parents are concerned for and love him/her, and thus allow the child freedom, but only in as much as it can be exercised without the child hurting him/herself.

As regression deepens, dependence upon the familiar and established order appears to extend to routines and inanimate objects. Patients need to have a predictable routine on which they can depend for security. They need to feel they still have some sense of control. If there are any variations from the routine the patient is apt to become very anxious. For this reason it is quite important to structure activities to meet the need of preserving the status quo and rendering the impression of stability. This also applies to inanimate objects. A misplaced toothbrush can be a catastrophe for the terminally ill patient when its usual placement is altered. Just like the neurotically compulsive individual, the terminally ill patient derives security from the precise ordering of the world. In this way the terminally ill still have some control.

## II. Defenses Aimed at Excluding the Threat or Its Significance from Awareness

### 1) Repression

The use of repression by the terminally ill patient facing imminent death is not surprising. Faced with the extreme stress of this situation, the patient forces the anxious thoughts and feelings about the condition into the unconscious. The patient attempts to exclude from conscious awareness those intolerable thoughts of death and its significance. Through this struggle the patient attempts to maintain an emotional equilibrium.

It is most probable, however, that this mechanism of repression plays only a small role for the patient since the symptoms are a constant reminder of the condition. This failure of repression to function adequately necessitates the emergence of auxiliary mechanisms aimed at exclusion of the threat from the patient's awareness. These include: suppression, denial, and rationalization.

2) Suppression,

In contrast to repression, suppression is the conscious attempt to dismiss anxiety-provoking thoughts from awareness. This is often accomplished through engaging in some kind of diversionary activity so as to push the anxious feelings out of consciousness by being busy with something else.

Such diversionary activities become more difficult to sustain as the fatally ill patient deteriorates. Suppression becomes weakened through the patient's increased idleness and passivity inherent in the bedridden state. Nighttime is especially trying for patients, for the lack of sensory input and the horizontal postion in bed deprive patients of possible diversions and leave them alone with their anxious thoughts. This may be one of several reasons accounting for the fact that the majority of hospital deaths occur during the night. To combat the stress that the night may pose patients may frequently get out of bed and move around. When patients are in the presence of others, they may resort to excessive talking or sleeping to keep dangerous thoughts at bay and to keep others from speaking of stressful matters.

It is extremely important to recognize that suppression is often necessary to the patient and should be supported instead of discouraged. One cannot continue to contemplate the issues posed by one's terminal illness without adequate respite. Suppression assists in affording some respite. "When nothing is to be gained from a therapeutic standpoint by encouraging expression of the patient's thoughts and feelings, he should be supported in his attempts to relegate fears to the back of his mind." (Verwoerdt, p. 64)

It must be noted here that misinterpretation of recent literature in the field has prompted some caregivers to feel that they must constantly bombard dying patients with questions and experiences designed to force them to discuss their terminal conditions and its implications. As will be discussed below with respect to denial, it is necessary and important to allow these patients to have some distance from the ever-present threat of their own demise.

### 3) Denial

The defensive process of denial is common to a greater or lesser degree in all patients with terminal illness. The mechanism is one of *avoidance* which the patient integrates into his adaptive system and which serves *to temporarily negate or render unconscious painful and intolerable thoughts and stimuli*. The process consumes energy and avoids reality but, at that moment makes life more tolerable for the patient. (Schoenberg and Senescu, 1970)

Most terminally ill patients exhibit three types of denial over the course of the illness (Weisman, 1972). Type I denial is a denial of the specific facts of the illness. Type II denial is the denial of the implications and extensions of the illness. Type III denial is that denial of mortality itself.

*Anyone who values life at all wants to deny death*. Green and Irish (1971) note "Evasion, avoidance and denial of death all have a rightful place in man's psychic economy. Man has a legitimate need to face away from death, and in truth, who is to say that under certain conditions this may not be salutory?" (p. 11-12)

Patients will vascilate between needing to deny that they are dying and being able to face their death. It is normal for individuals to want to deny their impending death. Many times, although a patient may intellectually accept and confront the fact that he/she is dying, the patient may deny some aspect or implication about their death which may be too painful to face, e.g., they admit they are dying but refuse to believe they are sick enough to have the doctor notify their children in order to say goodbye. Individuals who want and need to deny the fact that they are dying will do so even if they have been told the true condition of their illnesses. Thus the argument that some people should not be told of their illness because they will not be able to deny their illness in order to have time to mobilize their coping mechanisms, is invalid. A patient who does not want to hear the diagnosis, won't.

Many times the patient knows the true nature of the illness, but will not be able to admit it. This may be evidenced through "doctor hopping" in hope of finding a physician who can tell the patient he/she is not dying. When the patient knows, but will not verbally share the recognition of his condition with the doctor, the denial serves two important functions. Firstly, it renders the threat less real to the patient when it is not verbally addressed and brought out into the open. The matter still retains some qualities of the imagined or possible. The patient's worst fears are not validated. Secondly, if the patient refuses to talk to the doctor about the illness the threat can be pushed to the back of the mind and sublimated to decrease anxiety. Denial can also offer a respite from continual contemplation of the threat of demise. The terminal patient cannot and should not focus unrelentingly on death.

Some forms of denial absolutely should be respected and supported. Recent misperceptions of literature implying that denial is nontherapeutic and needs to be broken are grossly incorrect. If denial serves to hold the integrity of the individual together, then it is therapeutically useful. Schoenberg and Senescu (1970) state:

> "The emotional defenses of a patient should be respected unless there is clear evidence that the advantages of breaking down a patient's defenses outweigh the advantages of maintaining them. Confronting the patient with the evidence that he is dying may precipitate a reaction which can cause further depression, emotional disorganization, or further withdrawal from reality. Sudden disclosure of evidence may stimulate even more denial and make the patient less accessible..." (p. 231)

Therefore, it is evident that denial can frequently serve a useful purpose to the patient. It functions as a buffer to the shocking news of a terminal illness and then allows the patient time to collect the self and mobilize other less radical defenses. During the illness it may be intermittently employed if the patient is confronted with anxiety that becomes too overwhelming. It is usually only a temporary defense since most patients cannot continue to maintain it in the face of the illnesses, constant reminders of the truth.

Although some forms of denial are probably unavoidable in the course of a fatal illness, and may even be conducive to good illness adjustment, denial in its extreme form is highly detrimental. It can become self-destructive both physically and psychologically. Physically, patients can destroy themselves if they refuse to accept their conditions and neglect doctors' warnings and prescriptions. Psychologically, patients can destroy themselves if they refuse to drop their major denial. They slowly work themselves into a corner where they will eventually have to turn around and face the threat all at once. In addition, they will most probably be inefficient in effectively using their remaining time to clear up interpersonal relationships and to put affairs in order: i.e., "finish unfinished business." For patients to do these things would be to admit the fact that they are dying.

In most cases, the patient will vascillate between acceptance and denial. "Many terminally ill patients maintain a subtle equilibristic balance between realistic acceptance of death and its simultaneous rejection...this counterpoise seems to serve adaptational needs of the patients, allowing him to maintain communal associations and yet organize his resources to contend with oncoming death...both ideas of acceptance and rejection of death can coexist within the same person with acknowledgement and manageable fear generally dictating verbal or conscious considerations while denial and dread the 'gut' level reactions." (Green and Irish, p. 3)

4) Rationalization

Rationalization, which is one of the most common of all defense mechanisms, "represents a kind of reasoning whereby true causal relationships are not recognized, minor aspects of a situation are emphasized out of proportion or major aspects minimized so that the context is not perceived, or a non-attainable object or situation is devalued..." (Verwoerdt, 1966, p. 66). Aspects of the threat of death can then be explained away so as to deny its existence. For example, a patient may minimize the symptoms of pain as gastrointestinal problems instead of recognizing and admitting that the pain is symptomatic of the fatal illness.

5) Depersonalization

This defense is a very maladaptive one which operates through a blurring of the ego boundaries. In this process, the stress which the patient has to endure causes the boundaries of the ego to become less differentiated from external reality. Usually when these boundaries are intact and clearly differentiated, the personality identifying itself is intact and the external reality is perceived as being "something out there" and the self enjoys a feeling of sameness. Now, when through stress the boundaries become blurred, the distinction between the internal self and the external reality is not readily apparent. There is a feeling of unreality as the self loses its sense of sameness and experiences feelings of estrangement. The patient feels that everything around is foreign and strange. Patients feel as if they are detached and standing outside of life, observing it as an onlooker. Also in this defense reaction, patients may manifest symptoms of dissociation, wherein they feel that their experiences, and indeed sometimes their own bodies, are not part of them. This process allows patients to experience their illnesses without thinking about or feeling the impact that such an illness has come upon them. It is another way to deny the fact that it is he/she him/herself who is facing imminent death and is, in fact, dying.

### 6) Intellectualization

This defense mechanism isolates feelings from thoughts. Very simply, patients become observers of their own condition and do not permit any measure of their emotions to become involved. Such persons often appear intellectually preoccupied with their illnesses and also appear somewhat detached from it. They try to allay feelings of anxiety through exercise of intellectual and cognitive acts.

If intellectualization is carried on in moderation it can give the patient a sense of control and hope. If reading or discussion of the illness makes the patient envision the self as contributing to the larger universe (i.e., through the knowledge that the patient may help provide answers to research on this fatal illness, etc.), thereby making death have some meaning, the patient will be able to accept it with more equanimity. On the other hand, if the patient becomes too involved in the readings and developments of the illness, the patient may become anxious over anticipating circumstances and events which may never arrive. One woman became highly distressed over the fact that her illness had not run its course in the time allotted. If the patient, because of the use of intellectualization consistently denies feelings, then the defense is counter-therapeutic.

## III. Defenses Aimed at Mastering the Threat

### 1) Obsessive-Compulsive Mecharism

This mechanism relies heavily on intellectualization and isolation of feelings from thoughts. As implied previously, many patients attempt to master their illness and its resulting threat of death through a cognitive, intellectualized approach. When not too severe this detachment can be somewhat useful and anxiety-reducing.

It is as a result of these attempts at mastery and control over the illness that compulsive rituals and concerns may evolve. If these compulsions are not carried to the extreme and do not constrain the patient's personal sense of freedom, they can therapeutically be useful as they provide the patient with a sense of order, security, and control. Examples of this are the patients who have to have a fixed daily routine in order to help them function throughout the day.

### 2) Counterphobic Mechanisms

These mechanisms represent an attempt to master the threat by moving into the dangerous area itself. Patients who employ such defense mechanisms feel the need to disregard imposed restraints and to assert that they are the masters of the threat and not vice versa. For example, the patients who repeatedly drink alcohol despite doctors' orders to the contrary are actually trying to beat the threat of death. For such patients it is an attempt to assert that they still have control. In many cases the mechanisms of denial, rebellious protest, and over-compensation are associated with the counterphobic mechanism (Verwoerdt, 1966). Additionally, many patients combine this with intellectualization and isolation of affect in an attempt to master the threat intellectually.

### 3) Sublimation

This is a defense mechanism by which the individual channels unacceptable thoughts and feelings into socially and personally acceptable ones. In this way an outlet is provided for them. For example, a terminally ill person may be very angry at the way he was treated by his physician but instead of getting angry at the doctor, he may go and release his aggression through watching a boxing match or hitting golf balls. Often times, patients may direct their anger at being stricken with cancer into energy, attempting to work for such organizations as the American Cancer Society, etc. Caregivers should support the healthy use of such a mechanism.

## Variables Influencing the Responses of the Patient

The manner in which an individual responds to his terminal illness will be influenced by three classes of characteristics. (See also previous section "Factors Influencing the Grief Reaction" in submodule "Grief: The Emotional Reaction to Loss.")

The first class is personal characteristics. These include the individual's:

- Personality
- Age
- Coping Style
- Religion
- Social and cultural background
- Previous experiences with loss and death
- Maturity
- Intelligence
- Mental Health
- Fulfillment in Life

The second class of variables is interpersonal in nature. These include:

- Quality and quantity of the patient's relationships
- Degree of support and security provided by the patient's relationships

The third class of variables is specific to the illness of the patient. These include:

- Presence and amount of pain sustained
- Effects of mental and physical deterioration
- Effects of drugs and medications used
- Effects of treatment regimen, e.g., radiation, surgery, etc.
- Rate of loss of control
- Rate of progression toward death

## The Issues of Acceptance, Withdrawal and Detachment, and Hope

There are three issues which come up repeatedly in working with the terminally ill. The issue of acceptance on the part of the dying patient with regard to imminent loss, has recently been much debated. This controversy has resulted from the position taken by some clinicians and researchers that the goal of the therapeutic intervention with a terminally ill patient is to facilitate the acceptance of death. Many others question this goal and wonder whether it has been established for the sake of patients or for those working with them. Obviously, it is easier on all those concerned if a patient can accept imminent death with equanimity and peace.

Those who question, point out that it is natural to want to fight the fact that we must die. They cite the Dylan Thomas exhortation, "Do not go gentle into that good night...Rage, rage against the dying of the light." They contend that it is possible for a patient to experience a good death without having come to this state of acceptance, and its implied resignation.

A more appropriate description of what therapeutic attempts should facilitate has been provided by Humphrey (1980), a nurse with a long-time involvement with the dying. She notes that in actual clinical practice true acceptance (in the sense of the phase articulated by Elisabeth Kubler-Ross, in "On Death and Dying", 1969) is seldom witnessed. Instead, what seems to occur is a realization of the inevitable. An individual may still not be willing to go or be at peace with the fact that she/he is going to die, but it can be placed in the perspective that, for whatever reasons, the time has come. Accompanying this is the acceptance that death is a natural part of life and a fulfillment of the cycle of human existence. Although the patient may not be at peace with the fact that all that is loved must be lost, the patient is at peace with not denying the fact that it will occur.

The issue of withdrawal and detachment is important since it generates crucial treatment implications. Throughout this reading it has been asserted that dying patients need continued and rewarding interaction with others. There appears to be a clear mandate for family, friends, and health-care personnel to strive to make sure the abandonment, so frequently a part of the dying patient's experience, does not occur. However, there is a time, very close to death, when the patient starts to markedly restrict involvement with reality and the outside world (See also the section discussing "The fear of regression"). This is not to say that this had not been occurring to a smaller extent throughout the entire dying process, as indeed the patient has been slowly loosening the ties that bind, gradually moving toward a state of detachment and separation from that which must be left behind. At a point close to death, however, this now occurs with those most close to the patient and with whom the patient has still continued to be emotionally involved.

Humphrey (1980) makes the analogy that this experience of the dying patient in close proximity to his death is similar to that of the woman in labor. Initially, when the process began, the woman had an increased awareness of all that was going on around her. As she gets closer to birth, however, nothing and no one else really matters as she concentrates on the moment.

This withdrawal and detachment occur in similar fashion with the dying patient. The patient becomes involved in making the transition, in passing through a portal through which the journey must be made alone. In a sense, at this very end of life, the patient is not all here. It is as if the dying person had one foot in another world. The outward appearances signal that the patient has become introverted and withdrawn from the last things which he/she has been involved with on this earth. Frequently this is the family.

At this point there is a change in emphasis for care. No longer is the patient the one who requres the support; rather, it now becomes his loved ones. They may interpret the patient's turning away as rejection. They need to be helped to understand that this is not a rejection of them, but rather that all the patient's energies are now directed toward going where they cannot go. The patient's self-involvement is not a statement of lack of love, but a natural part of the process of death through which everyone passes. Intervention must be aimed at supporting the family at this time for the withdrawal and detachment may be difficult for them to accept, especially if they sense it as rejection.

Usually this last decathexis occurs in the very final hours of life. Clinicians need to differentiate this from some of the other gradual detachment that has been occurring already throughout the dying process. For, up until this point, it is still important to have significant loved ones around and to avoid the pitfall of abandoning the patient premacurely. Even at the every end, when the patient is withdrawn, it may be very meaningful to have a sense that the loved ones are still there. It must be repeated that one of the worst fears of any individual is to be left to die alone.

The third issue is one which deals with something that has been present from the moment of diagnosis: hope. The type and quality of hope will change throughout the course of the individual's terminal illness. Initially the hope is that the diagnosis will be proven incorrect. This changes, upon confirmation of the diagnosis, to the hope that there will be a cure or some miracle which will enable the patient to escape death. Later, this hope is transformed to a smaller scale and the patient hopes that life will be optimal, albeit limited, e.g., with a minimum of pain and disruption of lifestyle. These smaller hopes (known as "mini-hopes") related to everyday life may remain until the end.

Some degree of hope persists through all the phases of dying, through the emotional reactions, grief, and defensive procedures. Frequently, it is this hope that sustains the patient through suffering. When all hope becomes lost there is a psychological and then a physical surrender to the environment. Previous investigations of the survivors of concentration camps illustrate that the most torturous conditions can be survived if the individual has hope, as well as that the relinquishment of such hope is rapidly followed by death.

For this reason it is important to support hope in the patient. It is equally important to recognize that the focus of that hope may change, but that it is still an essential requirement for existence to continue; for the threat of demise to be confronted; and for the sustenance of meaning. Hope must never be destroyed. The informing of diagnosis and discussions with patients must never preclude the patient's being able to hang on to some hope, however tenuous. A patient can hear a terminal diagnosis and still have hopes for the type of life remaining.

## The Concept of "Appropriate Death"

The concept of "appropriate death" (Weisman and Hackett, 1961) is a quite useful one when dealing with terminally ill patients. Basically an "appropriate death" connotes a death with which the individual is relatively at ease or one which might have been chosen. With regard to a terminal illness the following criteria have been identified which facilitate a death with which the patient can "live" or accept.

- Conflict is reduced. Those things which may have posed internal conflicts for the patient have been addressed and worked through as much as possible, e.g., fears of loss of control, etc.
- Compatability with the "ego ideal" is achieved. This can be translated into "I am going to die as the person I think I am," i.e., the patient's basic sense of identity is maintained even in the approach to death
- Continuity with important relationships is preserved or restored. "Unfinished business" is attended to and the patient has the support of important others until death
- Consummation of a critical wish/concern is brought about. Critical last acts or last wishes are brought to fruition, e.g., the patient lives long enough to see the birth of a grandchild

Additionally, the individual should be as pain-free as possible, with suffering and emotional and social impoverishments kept to a minimum. Within the limits of the disability the patient should be operating on his/her optimum level of capacity to function.

An "appropriate death" will be different for each person. It can also be appropriate even if it is not accepted. Following Exercise IV, the next section will address the important issues and techniques for facilitating as appropriate a death for each individual as possible.

EXERCISE 1V

Consider what would constitute an "appropriate death" for you. (It need not be from a terminal illness). Jot down some of your thoughts.

______________________________________________

______________________________________________

______________________________________________

______________________________________________

What are ~~the~~ important criteria or variables which would make this death you noted above more "appropriate" for you? What things will be important for you to do or have?

______________________________________________

______________________________________________

______________________________________________

Do these criteria or variables have any implications for the manner in which you are, or should be, conducting your life now? (e.g., Do you need to start to make more time in your life for the people who are really important to you in order to have as little "unfinished business" as possible at the time of your death?) If so, what are they?

______________________________________________

______________________________________________

______________________________________________

What implications, if any, does this have for your working in Hospice?

______________________________________________

______________________________________________

______________________________________________

## The Nurse-Patient Relationship

In the terminal illness of any patient the relationship sustained with caregivers is extremely important. The patient has to have a great faith in these people in whose hands he/she literally places his/her life. These individuals become central figures in the life of a patient. It will ultimately become necessary that the patient enter into a dependency relationship with his/her caregivers so that it will be easier for them to provide care; for the patient to respond to it; and for the patient to accept vanishing self-control and autonomy.

The ideal goal of Hospice nurses is not only to allay the physical suffering of the patient as best as they possibly can, but it is also to help the patient prepare "for recognition and acceptance of this reality of life (death) so that they can undertake their last task in life with credit and dignity." (Verwoerdt, 1966, p. 6). It is evident that nurses play many roles for the terminally ill patient. Nurses are not only medical caregivers, but confidants, advisors, counselors, and therapists. They have the power to structure the patient's schedule so that it appears the patient has control over life and environment. They can support self-esteem by asking for the patient's opinions in matters which directly concern him/her and in which alternatives have to be chosen. They can arrange the patient's spatio-temporal relations in order to lend a feeling of security. As Verwoerdt (1964) notes, the doctor or nurse who performs these activities is supporting a regimen which will serve to function as an "ego prosthesis," which acts as an artificial ego by organizing the environment in ways emotionally supportive to the patient.

Recognizing the importance of the relationship between the nurse and the patient, it is disconcerting to note that as the patient draws nearer to death it is not uncommon for the health-care personnel, as well as numerous friends, acquaintances, and even family, to draw away from the patient. The main reason for this is that the patient reminds them that they, too, will have to face their own deaths someday, and for many the dying patient becomes too anxiety-provoking. Artsberry (1967) writes that nurses experience a sense of frustration, fear, uneasiness, and other unsatisfying feelings when they are caring for dying patients. Nurses will then tend to isolate themselves emotionally from the patient in an attempt to avoid facing their own death anxiety. This is easily perceived by patients and serves to contribute to the loneliness and alienation they are feeling. These reactions are not reserved solely for nurses or other health-care personnel. Similar reactions are observed in friends and relatives who may tend to eliminate their social contacts when the patient most needs them. All too often the following excuses are given: "I just don't know what to say. Maybe I should just leave him/her alone. It won't make any difference if I don't visit him/her in the hospital." This is sadly unfortunate, for patients do not want to be abandoned in their hour of greatest need and stress and they certainly do not want to be considered as hopeless cases.

In fatal illness the doctor and the nurse should allow the patient (following being informed honestly of the diagnosis and its meaning) to set the tempo in becoming more and more aware of the nature of the illness and its implications. Too much too soon can end in disaster. Too little can result in loss of faith in the doctor and nurse and, if the patient feels deceived or overprotected, may result in the establishment of a mutual pretense situation which robs the patient of opportunities to allay some anxieties by talking with health-care personnel who are also forced to maintain their part of the mutual pretense.

Schulz (1978) has written that of all of the needs of the dying patient, the three most crucial are the needs for control of pain, retaining dignity and self worth, and love and affection. In a quite unique way, the nurse is in a special capacity to address these needs. The final section will discuss the manner in which to do just this.

## Helping the Dying Patient

### 1) Prerequisites for Working with the Dying

There are some necessary prerequisites for those wishing to work with dying patients (Knott, 1975). These include:

- A personal confrontation with death in the sense of having started to come to grips with one's own mortality. This can never be done completely, but the issue needs to have been addressed

- An understanding of the grief process and an appreciation for the total experience of the dying patient
- Effective listening skills as well as the ability to respond appropriately. This attending behavior will necessarily be non-verbal as well as verbal
- A commitment to giving portions of oneself to the dying persons and to work (when appropriate) with the family after death
- A knowledge of one's own personal limits, the ability to know when there is a need to get away from death and how to respond to that need to avoid burn-out

### 2) Communication Skills for Working with the Dying

Verwoerdt (1966) suggests that communication with a terminally ill patient be directed toward three levels of understanding: (1) to the meaning of the illness and its symptoms to the patient; (2) to the patient's awareness of and psychological reactions to the illness; and (3) to the difficulties, fears and anxieties that the patient experiences as a result of his/her awareness and psychological reactions.

Counseling or helping the dying patient is the most non-directive form of assistance there can be. All cues must be taken from the patient him/herself. The most important way in which to help a dying patient is to listen actively, non-judgementally and with acceptance. In this way the patient can ventilate his emotions and feelings without fear. "Grief shared is grief diminished."

Communication skills include attending behavior and methods of facilitating communication. Attending behavior is that behavior that shows you are listening to the patient. This includes maintaining appropriate eye contact; attentive body language; and verbal following. Methods of facilitating communication include reflection of feeling; paraphrasing; the use of minimal encouragers; the use of open-ended versus closed questions; and eliciting the patient's own thoughts on the topic or question.

It is important not to force communication. The lead should be taken from the patient. If the patient does not wish to communicate at a particular time, let him/her know that this is alright and is respected and that you will be available if and when a talk is desired.

It is vitally important to remember that there is no way for the patient to "solve" the problem of his dying. However, there are ways in which we can share the attendant feelings and fears. Through open and sensitive communication with the dying patient we not only facilitate the ventilation of emotion, but we confirm the patient as a living, human being who we still support and about whom we still care.

### 3) Therapeutic Interventions - Help in the Experience of Dying

In making therapeutic interventions with dying patients it is important to have an appreciation for just what they think and feel. Many individuals have had prior experiences with loss, cancer and death in families and friends and these experiences have left them with fears, expectations, and misconceptions. Also, each individual operates out of a unique frame of reference and a particular social cultural and personal value system. Like the pre-morbid personality characteristics, these elements must be taken into consideration when determining how to be helpful to the dying. Related to this is the requisite of ascertaining the needs of the patient in order that the appropriate ones may be facilitated. A differential diagnosis (subtly conducted, of course) of the patient's fears of dying will allow for the identification of those requiring special intervention. Basically, all of this constitutes getting an accurate assessment of the patient's condition psychologically and emotionally, similar to what is done in the physical realm. Without such an assessment, clinical intervention may be ineffective, or worse, counter-productive.

It is important to remember that as circumstances and the illness cause changes, the patient changes too. Remember also, that all dying patients are not alike merely because they all have terminal illnesses. If these points can be kept in mind, the Hospice nurse will avoid the dangerous pitfalls of lumping all patients together and of thinking that one assessment of the patient is all that is required. Treat each patient as an individual and recognize that his/her thoughts, feelings, concerns, needs, fears, hopes, expectations, etc. will change over the course of the illness and will require that you respond to them as they do. Continuing re-evaluation is mandatory.

Krant (1977) delineates the responsibilities of the physician in decision-making in cases of terminal illness. These are also applicable to the nurse in the Hospice setting (and need not solely apply to decision-making).

- Deliver and interpret the technical information necessary for the decision. (Make sure the patient understands the information. Too often we hide behind medical terminology and jargon and although we may have "technically" given appropriate information, for all intents and purposes the patient has not been truly informed since he/she does not comprehend. At times this is done to avoid having to deal with the patient's reactions and it is an unhealthy and unfair game on the part of the health-care personnel. Therefore, make sure the patient understands the information you are conveying. Check out the perceptions of the patient if you are unsure of just how much he/she comprehends.)
- Facilitate meaningful discussion within patient and family limits
- Be alert to the values of the patient and the family
- Avoid undermining the patient's right to determine his/her own fate
- Provide a working team to facilitate the patient's understanding, control and communications

Krant (1977) also articulated interventions which are therapeutic when dealing with the dying individual:

- Spend adequate time with the patient who is mourning losses
- Continue reality testing
- Encourage verbalization of feelings of depression, anger, irritation, bitterness, sadness, and deep disappointment
- Surround the patient with empathic support
- Encourage the patient's initiative in discussion

In 1969, Pattison outlined what can be done to help the patient endure the dying process. He focused on ways to assist the patient in solving some of the problems inherent in the dying process so as to enhance self-esteem, dignity, and integrity. The results of this are that the patient can take pride in having faced the crisis of dying with hope, courage, and some measure of success. This is what Pattison calls "healthy dying". He describes the following six ways in which one can help the dying person to create an appropriate death;

- One can share the responsibility for the crisis of dying so that the patient has help in dealing with the first impact of anxiety and bewilderment
- One can clarify and define the realities of the day-to-day existence which can be dealt with by the patient. These are the realities of the patient's life
- One can make continued human contact available and rewarding
- One can assist in the separation from and grief over the realistic losses of family, body image, and self-control, while retaining communication and meaningful relationships with those who will be lost
- One can assume necessary body and ego functions for the patient without incurring shame or depreciation; can maintain respect for the person; and can help him to maintain his own self-respect
- One can encourage the person to work out an acceptance of the situation with dignity and integrity so that gradual regression may occur without conflict or guilt

In summary, the dying person should be approached as just that: a person. Just like other persons they need continued human contact; honesty in relationships; the respect accorded a human being; and assistance in coping with crisis, in this case, the crisis of death and termination of self.

## Death Across the Life Cycle

As the individual changes emotionally and cognitively throughout the life cycle, so too does conceptualization and attitudes toward death. This section will provide a brief overview of the identity tasks (so intimately related to any topic or event the individual confronts); the conceptions of death; and the issues of terminal status (see submodule on the "The Dying Patient" for a more thorough discussion on the important aspects) with which each individual copes during the major developmental phases of his/her life. Knowledge of these are critical to an appreciation of the framework out of which the patient is operating. Like cultural, religious, personality, and social attributes, these variables will influence the response to the threat of death, as well as to the experience of loss. They all react together to shape the unique response of each individual.

Much of the following discussion is based on the syntheses of Kastenbaum and Aisenberg (1972) and Pattison (1977).

- The Individual Under Three Years Old

Identity Tasks: The small child works on differentiating self from non-self. At this stage in life, the child requires the presence of significant others (usually parents) to maintain the sense of self and to provide constancy and security in the world. This world is primarily focused on body and parents.

Conceptions of Death: The child is not cognitively able to grasp the abstractions implied in the concept of death, e.g., irreversibility, finality, inevitability, and permanence, etc. However, children have definitely been exposed to experiences and behaviors which are relevant to death, e.g., periodic alternations of experience (separations, psychobiological biorhythms and environmental periodic routines); disappearance and return games (Peek-A-Boo); and things "all gone" (blowing out matches and flushing toilets, etc.).

Issues as a Terminal Patient: The child of this age most fears separation from parents. Therapeutic intervention will facilitate the constancy and closeness of these people to the child. If such significant others are unavailable for whatever reasons, a stable and reliable parent substitute must meet the child's need for love and help maintain the sense of being (Easson, 1970).

- The Individual From Three to Six Years Old

Identity Tasks: This child is developing the capacity to think, reflect, inquire, have self-control, initiative, and independence. This is the age of fantasy, daydream, and magical thinking. The child is very concerned with right and wrong, praise and punishment.

Conceptions of Death: The child begins to form an intellectual appreciation for death, but recognizes it not as final, but merely as a diminution of life. There is a belief that death is reversible or partial. Clear perceptions of death-related phenomena are possible, yet the intellectual frame work to completely understand or contain them are absent.

Issues as a Terminal Patient: This child tends to view illness as a punishment for real or imagined wrongdoings. The emotional reactions of parents are frequently misinterpreted as constituting anger or disappointment. The child becomes aware of what to say and not to say, so that his/her parents and others will not be frightened away. Separation from parents is still a critical issue. The child has much more of an idea that the illness is very serious than many, who might erroneously try to hide the fact, will realize. Therapeutic intervention will provide honest and rational explanations to dispel magical thinking and incorrect interpretations about the nature and implications of the illness. The child will be allowed and encouraged to communicate (whether verbally or non-verbally through play and art) in order to release the overabundance of emotions that have been aroused by the illness. There should not be too many changes in the environment or in the way the child has always been treated (i.e., things will continue as normally as is possible and advisable) since these changes may further contribute to a sense of insecurity. This applies for older patients as well.

- The Individual Who is Grade School Age

Identity Tasks: The child of this age experiences life to the fullest extent possible. The child is constantly doing, constantly acting, constantly experiencing. The child starts to define an identity through the all-important peer group and through a variety of accomplishments.

Conceptions of Death: Death is understood as a common finality of all living things. The youngster in this age group may personalize death, e.g., skeleton, Boogey Man. They may feel that their own personal death can be avoided. Toward the end of this age span, the adult concepts of death as final, universal, and inevitable are established.

Issues as a Terminal Patient: This child fears death itself, and is afraid of pain, medical procedures, and mutilation. The body has performed those acts which have provided self identity and to have it ravaged, or not to be able to utilize it maximally due to disability or dysfunction, assaults the capacity to be a person. Effective intervention will offer the concrete details of proposed medical interventions and will maximize the child's capabilities to do that which can be done. The child should still be provided access to friends. Surprises should be kept to a minimum and alternative skills should be encouraged to be developed.

- The Individual in Adolescence

Identity Tasks: Adolescents are intensely preoccupied with the self as they search to answer the question "Who am I?" A sense of respect for oneself as a unique human being deepens. There is a focus on the present and near future, with a rush and sense of urgency experienced as adolescents move from the present to the near future, eagerly awaiting the unfolding of identity. The distant future appears barren and the past is obscured.

Conception of Death: Adolescents sustain an adult concept of death. Now that they are establishing their own unique senses of self and identity, they are particularly vulnerable to the threat of death. Inherent in the process of the realization of identity is the realization that ultimately they are alone. The acute sense of individuality and aloneness of this age creates a particularly sharpened sense of personal mortality. The developing sense of self confronts a natural enemy in death, on the other side of the future.

Issues as a Terminal Patient: "The affirmation, confirmation, and clarification of the adolescent as a unique and real human being may be the most important task in coping with dying at this age." (Pattison, 1977, p. 23). Death anxiety, in an adult form, is clearly apparent. There may be a particularly strong sense of anger at being deprived of life when actually on the threshold of tasting its fullness. As with all other patients, regardless of age, this patient needs the opportunity for ventilation of feelings, answers to questions, and the maintenance of self-control, security, and relationships with significant others. (See Submodule on "The Dying Patient.")

- The Individual as a Young Adult

Identity Tasks: This individual is finally experiencing many beginnings of the fruitions of past hopes and labors. Careers, families, and relationships are in bloom. The individual focuses energy on nurturing them and experiencing their sweetness.

Conception of Death: Death is that inevitable event which is found in the future and feared as a threat to the fulfillment of life's goals and tasks.

Issues as a Terminal Patient: The dying young adult is filled with rage and anger for the interruption of his life at the moment of its fulfillment. There is frustration, rage, and a sense of unfairness and of being cheated. One struggles "to reconcile what might have been with what is." (Pattison, 1977, p. 24). The patient at this age holds on to existence more tenaciously than at any other age. The losses to be faced are especially acute. One is robbed of seeing the promise of life for self and significant others (especially children) fulfilled. Therapeutic intervention will focus on assisting the patient in working through as many of these losses as possible and in encouraging the necessary ventilation of feelings accompanying this. As noted in the section on "Helping the Dying Patient", communication and therapeutic intervention will focus on helping the patient to achieve "an appropriate death." This is especially difficult given that the individual has both more to lose and less to look back upon than at any other time in life. (See submodule on "The Dying Patient.")

- The Indivudual in Middle Age

Identity Tasks: At this point in life the individual is faced with the task of creating meaning, of being productive and creative, and is concerned with future generations (Erikson's "Generativity vs. Stagnation," 1950). There is a mellowing in personality and relationships. The development of these meaningful and ongoing relationships with spouse, children, and friends is important. Responsibilities and obligations to others are of the utmost concern. There is an ability to appreciate the more subtle and muted aspects of life.

Conception of Death: More intense awareness of aging and death is taking place and the individual is starting to "personalize death." (Rothstein, 1967). These persons have learned, at a deeper level, that they too can become older and die as they witness the death and debilitation of meaningful others. At first, there is shock in reaction to this and then there follows accommodation, change in expectancies, and acceptance of the inevitability of it.

Issues as a Terminal Patient: Death is the disruption of this individual's involvement with significant others. There is a concern over the responsibilities and obligations that will go unmet subsequent to death. Therapeutic intervention will assist in working through the losses of the patient and in the planning for those left behind. The individual may also need to look especially at the meaning of and marks left by his/her life.

- The Individual in Old Age

Identity Tasks: The individual of this age looks back upon life and reflects upon its experiences. This individual evaluates it with respect to the unique existence and identity of the self. There is an attempt at an emotional integration of the aspects of one's life, with the construction of meaning and an acceptance of one's one and only life as something with dignity and uniqueness that could have been lived in no other way. (Erikson's stage of "Ego Integrity vs. Despair," 1950).

Conception of Death: It is a gross exaggeration to say that the elderly are all at peace with their coming death. Some are and some are not. The elderly do appear to conceive of death as an important issue, of which they often think and for which they make plans.

Issues as a Terminal Patient: Those issues outlined in the submodule of "The Dying Patient" are equally pertinent to the individual who is elderly. It is an error to assume that advance age precludes the normal difficulties inherent in facing one's own death, and thus, therapeutic intervention must continue to facilitate "an appropriate death" for the aged individual. The individual's age might have some influence on the ability of significant others to be supportive, due to their inability secondary to advanced age. Additionally, support may not be as forthcoming due to the erroneous assumption that all elderly are prepared for their own deaths since they have lived full lives. In these cases external support from health-care personnel may be necessary.

The above has constituted a brief overview of the identity tasks, conceptions of death, and issues as a terminal patient that an individual encounters across the life cycle. The identity issues and cognitive/emotional sophistication of the death concept will exert strong influence on the responses of the terminally ill individual. Such responses need to be understood within these contexts in order that effective therapeutic intervention be directed toward the issues appropriate to the patient at the time of illness.

Interventions that reflect an understanding of the particular cycle of life of the patient will greatly enhance the Hospice nurse's ability to respond to the personal and unique needs of those to whom care is given.

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# FACING DEATH

Robert Kavanaugh

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# CONFRONTING DEATH-RELATED FEELINGS

Robert Kavanaugh

Aside from stamping ants on sidewalks, my first experience with death, as best I can recall, happened in early second grade. Several of the seven Kavanaugh brothers found our dog, Sandy, dead and nearly frozen in the woods behind our house. Crow hunters had done it. By accident, we hoped.

Sandy was no ordinary dog. He had seven young masters for loving and teasing, for wrestling and obeying. Dad was his big boss and Sandy abandoned everyone else when Dad beeped the car horn to the tune of "Shave and a Haircut, Two Bits." Sandy feared Mother who broomed him into the basement each night, yet he loved her because she fed and watered him.

My shock and sadness came out in private tears. Anger came and jealousy, too. I almost hated the man who offered a puppy in quick replacement. I watched other dogs, wondering why Sandy had had to die instead of those mutts. Rage came out in our late night plans to stalk the next hunting party we saw. However, the best grief therapy was in planning and performing a solemn high mass for Sandy's funeral.

After all, Sandy was a Catholic. While playing priest we had baptized him, laughing at his muskrat look as water oozed over his head, admiring his obedience when the lighted baptismal candle touched his paw and blessed salt touched his long tongue. Playing bishop, we had confirmed him, too, complete with olive oil and a sound slap on the cheek. Often we slipped him a white Necco wafer, the color nobody liked, when he looked hungry at communion time.

I wonder if any canine requiem could ever compare to Sandy's. Three youthful self-ordained priests presided, one eulogized. His cardboard casket was covered with a black pall, lowered away to an off-key Gregorian chant. Mother made the priestly vestments, and we served lots of his favorate Necco wafers, white ones, to all the Protestant kids who came to gawk. We buried him in ground blessed with our own homemade holy water. Then we rolled a huge rock over his grave.

In retrospect, it all sounds so cute and boyish. At the time it was not. It was sad and upsetting, somewhat frightening. I felt uneasy digging a grave, lifting my dead dog, throwing dirt over him, all the while wondering if there might be a dog heaven. My teacher, Sister Mary, said there well could be. I think I prayed for Sandy every time we walked along the path where we laid him, in case there was a purgatory for dogs, too.

Our past lives are invariably dotted with Sandy-like scenarios. Yet, most Americans have no more than shadowy indications of their true feelings about death. Ask friends how they feel about dying or death, and you will hear how they would like to feel or how they think they ought to feel. Our society frowns on any open discussion of so gruesome a topic. Actual feelings remain buried within secret caverns of the self, never fully searched out, so never squarely faced or fully experienced.

Psychologists increasingly insist that our death-related emotions affect the quality and the style of our daily life. They can influence the way we drive a car, our habits of eating and drinking, the way we exercise. How much we sleep, what pills or drugs we use, our spirit of adventure, even the degree of our commitment in love can all be severely affected by hidden and unresolved qualms about death. A good example is insomnia, where restful sleep is difficult because it is feared as an imitation of death. We become especially aware of our feelings as they seem to surface and ignite unaccustomed turbulence when we feel obligated to visit a friend who has terminal cancer, or attend a poignant funeral.

While I was teaching an extension course at the University of California at San Diego on thanatology, it became clear to me that an honest and humane approach to death can begin only when we allow ourselves to get in touch with our visceral *feelings*. Otherwise, any stance we adopt toward death will be no more than another form of blocking and avoiding honest confrontation. It is not the dying or the dead we fear as much as the unknown and untested *feelings* they evoke within ourselves.

A well-known biochemist liked to advertise his fearlessness during a recent bout with death. While describing this experience to my class, however, his usually bombastic manner faded into an unfamiliar softness. His loud and energetic voice constricted into a wistfulness barely audible beyond the first few rows. Never had I heard my friend so controlled.

In my classes, students regularly mocked adult fears and what they felt was our undue concern with the individual's inevitable end. I mistook their bravado for bravery until I realized how many of them were rapping on death as they did on sex, merely as interested virgins. Rarely had they lost someone close or yet known a relationship seasoned by years of mutual intimacy from which they might imagine the grief that such a human loss can bring. Inexperience had a sense of being special, even omnipotent, left them unable to get beyond head trips in our class discussions.

Older students who professed no fear of death were often strangely unable to attend regular class sessions where articulate men spilled unalloyed feelings about death and afterlife. Excuses were amusing. Even among those attending, an abundance of glassy eyes suggested their minds too frequently were on jaunts to more pleasant subjects.

Death does not permit objectivity. At birth it is too late. All of us are subjectively involved, because each of us is always dying. Those we designate as "dying" differ only in that they know the nearness, while all know the inevitability. We assume a variety of masks to pretend we are objective when we only mean we are controlled. The basic mask all humans put on is to call ourselves "the living," when we are equally "the dying."

Doctors and nurses can use white uniforms and speak their Greek-rooted gobbledygook instead of clear English. Stethoscopes, pain-killers, thermometers, bandage changing, tube arranging, busy schedules, endless charts and hierarchical buck-passing, all are important parts of a routine designed to help them remain a few steps away from raw confrontation with expiring patients.

Clergymen, too, have face-saving escapes. Clerical garb, titles and unfamiliar language can keep patients at a distance. Ritual sacraments, Bible readings, silent prayers and hospital rules can rescue uneasy clergymen from any but casual involvement.

Funeral directors use a host of clever shields against each fresh contact with open grief. They have invented an entire language of euphemisms and they gently force the bereaved to learn and speak it. Canned advice and inspirational quotes may sound spontaneous to each new mourner when they are only planned techniques to avoid words from the heart. Mourners are kept busily engaged in deciding, selecting, signing papers, always in a routine neatly designed to prevent emotions from erupting.

Honest laymen know these facades. They mutter at the ghastliness of visiting open caskets or how, if dying, they would want to be left alone, thus enabling them, reasonably and righteously, to stay away from both the dead and the dying. Laymen know, too, of reverse masks, where grief is feigned for business purposes and funerals are used as fine occasions to meet the proper people.

Society recognizes that there are times when every human being needs to don a mask. Medics may unashamedly wear theirs when wards or caseloads reek too heavily of dying. Clergymen and morticians properly feel guiltless when demands surpass their personal strength. Human limitations require that we invest only so much of self in the loss and grief of others. No man can rightfully tell another how far to push himself.

Honest recognition of our latent feelings about human mortality enables us to be free enough to make some choices. Only when we know our feelings can we respect our unique reactions. No longer need we pummel and even smash our emotional selves behind artificial defenses. Once free, we can choose the masks we want or need, even sometimes going maskless, instead of compulsively avoiding the reality of all death and grief because we lack the humility and courage to be any other way.

Most people I observe don their masks compulsively. Some of our masks are cruel, demeaning, inflammatory or actually harmful to patients and families, reflecting a coldness we do not feel, a curtness, an indifference, a sense of being too busy. Once we become aware of our rigid, compulsive behavior, we may start to find some freedom of choice, and alternative stances are possible. Professionals and laymen can select a shield that fits the situation, respecting personal needs and limitations and the needs of folks they visit. It helps immensely for professionals to inspect the mask they wear, encouraging honest feedback from patients or families. Those who believe their traditional stance is one of objectivity may soon learn how narrow the line is between objectivity and coldness.

Even uniquely strong human beings rarely reach a consistently comfortable and gracious posture in the presence of human death. No matter how many patients they visit or tend, no matter how many times they are partners in grief, their unresolved feelings cause internal distress and withdrawal behind their pretenses of warmth and concern.

No books or conferences, no movies or discussions, will be effective, ultimately, in helping us master the art of peace and graciousness near death, until we permit our feelings to be honestly and fully felt, and admit it is all right to feel as we do. Until then, newly acquired skills will be no more than fresh evasions.

Only some uneasiness and fear will disappear when we succeed in opening up. Much will remain as part of our cultural heritage. We will not grow instantly brave, only gradually less fearful of being human, of owning up to the reality of self. What is so wrong with feeling a modicum of fear and uneasiness without running to hide? Such feelings are as normal and natural as death.

Once we discover the nature and extent of our visceral feelings, it helps to counterattack. It facilitates growth to experience what we fear without trying so hard to mask our reactions. Uneasy in the presence of the dying? Visit them and stay longer than needed. Fearful of open tears? Visit grief-stricken friends. Uncomfortable at wakes and funerals? Go! And soon we will find that others can accept our clumsiness whenever we can. In fact, the clumsiness of professionals and friends grants to patients and their families permission to exhibit tears and awkwardness they never dared display before.

I would prefer the clammy or trembling hand of someone than no hand at all. In fact, I would never know if the moisture and shakes were theirs or mine. I would prefer a doctor who stuttered and lost some dignity in tears than to be continually chilled by professional aloofness. I would rather a friend came and dumped his own fears than to grieve alone or with too fearless a friend. I could gain far more from a mortician with a real tear in his eye and a real quiver in his voice than from one with impeccable control and modulated emotions. Humaneness triggers humaneness. Warmth generates warmth. For practiced and unpracticed alike, it is normal to feel uneasy around death. And it is not abnormal to admit or show it.

I can recommend two approaches helpful to many in exposing death-related feelings. First, a reflective journey back through life, focusing carefully on experiences that possibly formed present attitudes. If your early life, prior to this time, has been touched by death, you may well capture again many of the original emotions. Clues will arise as to what is buried inside, what was never fully experienced before, what is unfinished grief, as distance lends courage and perspective not had before.

Those with few or no death-tinged experiences in their past will undoubtedly find the vacuum now filled with fantasies grown up out of ignorance, suspicion, invention or hearsay. Maybe fantasies were ballooned out of proportion by horror movies, or murder mysteries. Their fears may be no more than echoes of other people's fears, easily dispelled by their own first-hand experiences.

A second approach I value consists in carefully reflecting on death fears admitted by others. Any list of such fears contains common chords, major and minor. By careful sorting and musing, by discussion and the refusal to run away, can come the freedom and permission to own what we truly fear. To buy into our deep-seated fears is to begin to deal therapeutically with them, to dissipate some, while insuring others will not force us into a phony or compulsive stance when death comes close.

The remainder of this chapter contains my own reflections on death in my past. Hopefully, my thoughts can serve as facilitators to your own. My attempts at honesty might unleash yours. In the following chapter, I report an interview with an exceptional woman who willingly shared the litany of fears she identified in living and in dying.

Shortly after the funeral of our dog Sandy, Sister Bridget, my third grade teacher, appointed me an alter boy. I recall serving at my first funeral early in third grade, the first of more than 400. Another alter boy and I accompanied our priest to the home where the casket lay in the living room, banked by flowers. As Father blessed the body and lowered the lid, I peeked in for my first glimpse of a human corpse. It was an old man I had never seen before. When the finality of the thudding lid caused a chorus of moans and sobbing tears, shivers went up and down me, all over.

Spookiness best describes my feelings, and thereafter, every association with death took on a spooky air. Funeral homes, coffins, dying people, hearses, cemeteries, old-age homes and floral shops alike! At that time I began to trade purple jelly beans, because they tasted to me the way funerals smelled.

Father led the funeral procession to church, flag on fender, motorcycle policeman directing; I felt terribly important. During mass I kept glancing back at the casket in the center aisle, also eyeing the mourners sobbing in the front pews. After mass I held Father's cope as he circled the casket, sprinkling holy water and incensing the body. The more I tried avoiding the casket, the more I bumped it. And spookiness each time.

It was a relief to sit down for the sermon by our Monsignor, but not for long. It was the shortest funeral sermon I have ever heard.

In fairness, you should know a mite about Monsignor before you hear of his sermon. Armed with an episcopal mandate to inspire our parish with the best in good example, Monsignor led us back from the scandal of a neighboring pastor marrying his housekeeper and the still greater scandal of our own pastor being killed by the gun of his crazed assistant pastor. Monsignor took his leading seriously, especially at funerals.

Picture this steely-haired cleric standing in the opening of the communion railing, staring in silence at the casket for fully a minute. Slowly pointing his finger at the casket, and in his mildest snarling tone, he fairly growled: "If the top of that casket suddenly popped open and old John sat up, he wouldn't know where he was. He was never inside this church a day in his life. Pray for him! In the name of the Father and of the Son and of the Holy Ghost. Amen." Amen! Things were different then. You can guess who was ahead of me in the line outside Monsignor's confessional the next Saturday. John's widow.

In primary grades, we learned a lot about hell, a little about heaven and loads about purgatory. Purgatory was as high as most dared aspire. Each night I concentrated fervently on my act of contrition, hoping it would prove perfect enough to avoid hell if I died during the night like so many kids did in the scary stories Sister told. The list of people I needed to pray for lengthened nightly, including every relative and friend, nuns and priests, garbage men and new bus drivers. To forget a name meant putting them in spiritual jeopardy and me in danger of purgatory for not loving properly.

Through grade and high school, I averaged three funerals per month. We went less and less to homes, increasingly to funeral homes, until undertakers replaced priests as casket-closers, then we only went to church. Such relief. Nothing so adversely affected my attitudes toward death as the wails and groans when caskets were closed and sometimes reopened, occasionally over and over, until every bystander was paralyzed in tears, including one little alter boy.

Usually I cried too at Italian funerals or when taps echoed for vets. Rarely did I know the deceased, but at less emotional funerals I felt guilty for not shedding a tear. I confessed my failing and my confessor assured me it was no sin. "It is normal not to cry for strangers."

At times we accompanied Father on early morning communion calls to the bedridden. We knelt next to the bed, reciting the Latin confiteor and holding the paten under the chins of nuns, the crippled, mental patients, the aged of every description, many about to die. The nuns looked funny with linen bonnets pulled over badly shaved heads, solving a mystery for one who always wondered what Sister did with her hair.

During alter boy days, I witnessed the grief-style, funeral customs and burial procedures of every type of family in our parish melting pot. We buried Slavs and Italians, Poles and Mexicans, Germans and Irish, French and Indians, Orientals and those of African ancestry. I learned how it was done for politicians and bishops, for nuns and priests, for babies and children, for vagrants and entire families, for veterans of World War II.

Highly influential in forming my feelings were the scenes at graveside. Italian mothers sometimes threw themselves on the casket and had to be pried loose. Relatives would beg for a final look at the deceased and collapse in hysteria. Tears were always louder, sobbing harder. More than once I was needed to tote a vagrant to his final resting place, no friends for pallbearers, no funds for stand-ins, no parishioners available. Even the most stoic families were driven to open grief by the sight of a gaping grave and piles of dirt.

No relief could equal mine when Father closed his Latin book and moved toward the final handshake with the next of kin. That was every alter boy's signal to break for Father's car, escaping the awful lowering of the casket and the tenseness of dirt on concrete.

Alice Dickens sat in front of me in fifth grade before she died. As the entire fifth grade marched in ranks to Donovan's Funeral Home for her rosary, I regretted teasing her, stuffing her pigtails in my inkwell and muttering under my breath when she tried to recite. As Hail Marys droned on, I craned to see her in the coffin. Afterwards, my friend Sammy nudged me to stay. When nobody was noticing, he touched her hand, daring me to do the same. But I was afraid. For many nights afterwards I tossed in bed, imagining her hand in mine. And her hand was cold and dead.

I can still remember seeing shiny black hearses, curtained, mysterious, gliding down our street, pausing in front of houses, finally stopping, body carried out, casket carried in, floral marker on the door, people trooping in and out, then draped windows and black clothes for many months. One of our tribe of seven brothers reluctantly took mother's meatloaf and chocolate cake to the door, peeking inside. (Once baby Danny asked if dead people ate meatloaf and chocolate cake.) For hours the neighborhood gang would congregate across the street, down a ways, peering, looking nonchalant, hoping to glimpse a dead body, fearing we might.

When our grandmother lay dying--we called her "Ma"--six little boys stood and squirmed outside her door in the hallway of her flat, while an even smaller one crawled along the floor. Uncles and aunts were generous with nickles for being good which meant being quiet. Sometimes we opened Ma's door for a "Hi, Ma!" but Ma never returned our "Hi!" She looked awful. The doctor came with his black bag and showed us his colored pills. Father came for Latin prayers and we knelt respectfully. Then they took us to Aunt Vern's and everyone said Ma was dead.

Ma looked almost alive in her casket and it was not spooky at her funeral. Her grandsons served, and even when I bumped her casket nothing happened. Afte all, Ma was inside. I knew and loved her. Even the cemetery was not sinister when Pa and Mother and my aunts cried. I think I cried, too.

One night at supper, Dad announced I had just been offered a job with one of his friends. Night watchman and clerk at a funeral home. The only duties were answering the phone, a little dusting and watching for prowlers.

My new boss showed me his palatial mortuary. I closed my eyes in the casket display room, lowered them and held my breath in the embalming room and secretly held my nose as we inspected the chapels where flowers surrounded two caskets. He showed me the tiny office where I would await grief in the night. Outside the window, two black hearses stood poised for my command.

The pay sounded good. Dad never understood why I never began, probably accusing me in his own mind of ingratitude instead of the real reason: the place spooked me.

One Sunday evening a bad accident happened on our corner. Dad carried one victim inside, laying him on the davenport under a blanket. He was bleeding badly when men came to take him away. Nobody told me but I believe he died on our couch. Whenever Mother was gone long enough for us to wrestle in the living room, I always tumbled my opponent off the davenport, quickly.

Outwardly it was fun the Halloween we dared to "Trick or Treat" at a funeral home. Laughing boisterously, we knocked until the undertaker came. He invited us to wait inside while he solemnly departed along a darkened corridor to a distant room. On a dare, I opened the door where he had been. The naked body of an old woman lay on the embalming table and even now I feel guilty for invading her privacy.

Cemetaries were eerie places for me and my friends. One summer I worked trimming around tombstones, memorizing "Casey at the Bat" and most of Robert Service and Edgar Allan Poe while snipping around old graves. I did not often join our gang in their necking parties inside the Protestant cemetary. I know only Catholic cemeteries were consecrated ground, but I am not certain now whether sacredness, spookiness or girls were more frightening.

At age seventeen I entered the seminary which admiring friends slippingly called the cemetary. My new status kept me out of the draft for World War II. I felt guilty over those years when seven schoolmates were killed, and doubly so when their mothers hugged me at their wakes, telling me how lucky my mother was to have me far away from war and death.

Little did those grieving women know how truly far removed the seminary was from the global conflict and carnage. My life view narrowed in a narcissistic concern for: my studies, my sports, my health and my spiritual life. My solipsism-in-action earned me the family title of "King Seminarian." Once we sang at a bishop's funeral, once we waked and buried our rector, and once we buried an elderly nun whose path to sanctity was in the seminary kitchen. My distance from all dying grew and religion added new controls. In nostalgic backward glances, I now see the seeds of the avoidance methods so many clergymen use.

Our seminary specialized in avoidance. No contact with the outside world beyond the daily sports page on the bulletin board or a box of cookies from home. We were encouraged to sever every important human tie, any bonds that would make parting painful, in the interest of serving all men equally. In their zeal to mold us into men of that world where death has no victory, our spiritual directors concentrated their fire on our cliques and close friendships as well as family relations.

Later, we spent months studying the last rites and all the bizarre circumstances we might face. Accident victims along the highway, people entrapped in tunnels or fiery buildings, prisoners hanged or electrocuted, soldiers maimed in battle. We schemed endlessly of different ways to approach backsliders or to talk the reluctant into receiving the sacraments. Practicing for rites that could change men's eternities without once coming within miles of a dying person. All theory, no laboratory.

Our moral theology professor clocked our dash to the spiritual rescue, unable to pass unless we could complete the last rites in less than 45 seconds. Later I knew the value in such training. Catholics expected quickie sacraments and rarely complained. They usually believed the last rites might achieve what they never were intended to do: rectify the relationship of an unconscious or dead man with his God. Relatives applauded the briefest visit, always understanding "How busy you are, Father," even when we sneaked into a morgue to anoint a cold body under the theological theory that souls might not leave bodies for at least three hours after medical death.

Our seminary offered no lessons on facing the dying patient as a human being with fears and maybe terror. No skills were imparted on how to assist the bereaved. I brought little more understanding to my early sick calls than Mother had taught at home: Be kind, gentle and thoughtful, As I ran quickly in and out of homes and hospitals, to accidents or tragedies, reading Latin prayers, absolving, anointing, another set of conflicting values rose within me. I began to feel the need to stay and mourn a while, to chat and listen a bit, to say English prayers, to serve as a sounding board for the grief of frightened men and women, dying or grieving.

The human anguish around the dying could be "honorably" bypassed with hurried rites and flimsy excuses. Any excuse Father offered was a holy one. Soon I believed the dying were often more in need of present comfort than of forgiveness for the future. Slowly and painfully, my needs to stay near the deathbed won out. I remember the night of the final breakthrough.

In the polio epidemic of 1953, I stood all night with a family of nine while number ten, a seventeen-year-old girl, struggled in an iron lung. She watched in a mirror as the ten of use rose in unison, heal and toe, toe and heel, matching each whispering breath of that giant machine. She refused the last rites, satisfied with the comfort human presence could bring. Then she died.

Despite an all-night vigil, I needed no extra sleep. A new buoyancy came from attacking my fears. Still feeling spooky inside, still cowardly and conditioned to run to a quiet rectory, I finally found the courage to stay and be afraid. Now it was possible to confront death head-on with only inward apprehension and no evasion. I could even cry in front of people. Now the only problem was when to leave a deathbed scene. No books told. There were few models to imitate and little counseling from peers who largely followed the "quickie" route.

Most of my priestly work was among college students. No death seemed more tragic than the suicide of a bright nineteen-year-old, unless it was the death of a beauty queen from a clumsy and illegal abortion. Nothing in the world of the young offered a single clue to understanding death. It was easy for a frightened man to be a hero in the land of the naive. My mission was less difficult because of a burning conviction that death meant mere entrance into eternal happiness, possible even for Protestants, Jews and non-believers. This conviction eased my fears. It did not remove them.

Death struck personally close when twice I heard my surgeon say: "I think we got it all." The "it" both times was beginning cancer. On neither occasion was death a remote prospect. Maybe unreality came from my being employed by God. Maybe from the joviality of the surgeon whose favorite mask was joking. Most likely, death seemed unreal because it never happened to spectators like me.

The final and most decisive experience occured in my adult life. A very close friend and I were hospitalized at the same time. One afternoon he suggested a stroll around the park-like grounds, but hospital schedules prevented my joining him. That night I heard the news that this brilliant, athletic and strikingly handsome priest, thirty-six years of age, had been found dead in the woods. Hospital authorities announced that he had slipped and hit his head on a rock. I thought differently. His parents were arriving the following day and he feared telling them of his desire to leave the priesthood. Nobody in authority knew his faith had dwindled, maybe disappeared. I was the last human being to see him alive. Nobody asked me a question. The Catholic authorities at the hospital and in his religious order believed what they needed to believe: it was an accident.

Reflecting on this tragic waste of human beauty and goodness, I knew life here was paramount. Had my friend requested a sacrament from me, hospital rules would not have stopped me. He asked instead for a human presence, and I was not there. I did not then shed my belief in afterlife, rather I began to comprehend how much less it mattered.

Now outside the norms of traditional theology and church discipline, I find it frightening at times to live without instant explanations for death. It has been comforting in the past to explain tragic death in terms of divine justice, citing God's permissive will. For the first time I feel the perplexity and futility of all who listened to my former explanations. Now I realize they listened more to me and my concerns than to my endless words.

Pressure to accept easy explanations grows greater now as the body ages, losing its vitality, with creaking joints, saggings everywhere, constant bruises and perdurable aches. The signs of aging are only real when they happen to yourself. Recently I noticed how the mirror only reflects my face. Faces grow old gradually, almost imperceptible to the owner.

The softening of my official and clerical stance permits a more balanced view of the entire subject of human mortality. I better understand unbelievers and undertakers, forlorn husbands and fatherless children, doctors and suicide victims. No longer do I view every tragic death in a religious context before it is humanly felt. For the first time, I find hospital and burial bills real. Priests were healed and buried at discount.

To dying and bereaved friends, I offer no magic or myths, few consoling words. Myself is all I have to offer, my freedom, my fear and uneasiness, my warmth and concern, my willingness to hear any viewpoint, even despair. I have no oils for anointing, but my hand can be held. No ritual to read, but my eyes can return an honest gaze. No busy schedule, only time to sit near the bed of anyone I love, or maybe in a corner, offering presence in their privacy. No need to fear my uniform or even fear shocking me with outlandish beliefs or blasphemous attitudes.

Now I have a family and can allow people near me to need and want me. I can openly admit I do not want to go away. Gone is the posture of false bravado and omnipotence. At last I feel human enough to die.

A personal God may be one breath away. If so, I will try to love Him as I try to love the folks I meet each day. I cannot believe He cares about my rejecting or adopting a creed that will not alter my life. Nor that oils and blessings with a few muttered words can change my eternity. Any credible God will understand the search of one who believed before he switched to Pablum, who prayed before he said "da, da" clearly and who blessed himself before he walked.

So much for my experiences and reflections. Before reading further, I suggest you pause and spend whatever time you need to put your death-affected experiences in focus. Allow yourself to feel what you feel. It can be painful to see again your dying cat, your puppy hit by a car or to relive your grandpa's funeral. It hurts to recall an accident that killed your favorite friend or the suicide of a relative, the funeral of a baby brother. It takes time to recreate the death-style in your family home, the folk wisdom, the religious answers, the fears, the silence and the reaction to tragedy. If you are patient and persistent, your actual feelings may float to the surface. Maybe you will find you are less fearful or uneasy than you thought. Assuredly you can find the source of your reluctance to visit dying friends, to attend funerals or to call on the bereaved.

Let me reassure you it is okay to feel uneasy or afraid. It is okay to want to run, to send floral wreaths or mass cards instead of self. It is okay to feel eerie or unduly tense, to hide and cry, to want to swear or scream or lash out at easy targets. It is okay to feel relieved and even happy when someone dies. It is okay to feel whatever is real. Feelings have no morality. They are neither good nor bad, always ethically neutral.

Too long have we misinterpreted the ancient wisdom of saying nothing about the dead unless it is good. Properly interpreted, it means we ought not talk publicly about the private faults of the dead. If stymied, it is better to say nothing than to violate a trust of close association. Misinterpreted, this adage leads so many to deny their honest feelings about the dead in their past, either privately to themselves or confidentially to a trusted friend. Maybe you loved your parents but secretly resented them for dying when or how they did. It is okay to face that fact as you reflect and to own the feelings it generates. It is also okay to talk about your "odd" feelings with a friend.

Few human relationships can ever be characterized as exclusively bonds of love and fondness. Our ties to each other are far more complex. Often love coexists with fierce hate, and rage commingles with the deepest warmth. Violent emotions of every kind can be locked in hearts too frightened to find out how they truly feel about dying.

It takes time and tiring work to unearth the untouched feelings in our past. The promise is worth the effort. At the other end of the emotional gauntlet lies the art of graciousness near death, the personal freedom to die in peace and dignity, to help others die the same and to comfort grieving friends with more than sympathy cards and contributions to their favorite fund. I hope you can accept the challenge.

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# SUMMARY OF THE SALUTARY CONSEQUENCES OF DEATH

Peter Kosetenbaum

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Koestenbaum, Peter.  "The Vitality of Death" OMEGA, Vol. 2, No. 4, 1972.
Pgs. 269-71.

## SUMMARY OF THE SALUTARY CONSEQUENCES OF DEATH

Peter Kosetenbaum

Let us summarize the salient features of the positive and salutary aspects of the fact of death.

1. Man cannot escape death-real or symbolic. He must construct his life-daily actions as well as major, overall plans--with the full and clear realization of that fact. He must accept, once and for all and without any reservation, misgiving, false hope, repression, or bitterness, the fact that he has been condemned to death. Then he can start living. In accepting death, he will neutralize an otherwise completely demoralizing and paralyzing fear. This is one key to the successful management of human existence.

2. Once he has recognized and admitted the inevitability of his death, the individual is on the way to becoming courageous, fearless and decisive. Whenever he feels indecision and lack of courage, he must remind himself that life will end for him. The symbolic threat of death, which often is the cause of his indecision, will then disappear, since its basic fraudulence will have been made manifest. He will be able once more to steer his life with courage and decisiveness.

3. By remembering the certainty and finality of death, man immediately sees the urgency of concentrating on essentials. He cuts red tape in his life. He abandons excuses and procrastinations. He does not indulge in the luxury of wasting time--under the guise of getting work done--by getting lost in an endless amount of detail and busywork.

4. Only through the constant awareness of death will an individual achieve integrity and consistency with his principles. Since there is, basically, no threat other than real or symbolic death, and since he has accepted that threat, he is well beyond fraudulent bribes and threats alike. In the last analysis, all man owns is the integrity of his character. No one can threaten him in the matter of his principles, since he is always in the presence of the ultimate threat anyway. What criminal would think of holding up a convict on the way to the death chamber?

5. The man who knows he will die wastes no time in attacking the problem of finding meaning and fulfillment in life. The pressure of the thought of death is a persistent and nagging (and most effective) reminder that he is coerced to make some sense of his life, and that he is to do it now. He who has faced death adopts a no-nonsense approach to the business of living successfully.

Precisely what these goals are is an individual choice. It may not be desirable to be burdened with such choice; but it is a fact of life that every man must commit himself personally to whatever values he chooses to consider highest. We all have strong predilections; we all have some idea of what it is we really want. Under pressure of death we will quickly dedicate ourselves to these goals. Existentialism is not an ethical commitment or a normative proposal on how life should be conducted. As a philosopher, the existentialist cannot decide questions of ultimate values. Existentialism is a theory of man, and as such it either corresponds to the facts of lived experience, in which case the theory is true, or it does not correspond, in which case the theory is false. Existentialism is religiously and axiologically neutral. Death is a fact of life that is a universal truth. The recognition of the nature of the anticipation of death has rejuvenating and revitalizing effects on human existence. That is another fact of life. What the decision is, or should be, about the meaning of life is, perhaps unfortunately, a burdensome individual decision. But the decision will come--since we often know what we really want--as soon as the urgency of reaching a conclusion is brought home to us through the fact of inexorable death.

6. The vitality of death lies in that it makes almost impossible the repression of unpleasant but important realities. We do not accept any excuses to postpone dealing with our basic problems or to hide these from ourselves. The realization of death carries with it the successful management of many unconscious and repressed problems. He who is about to die does not practice the art of self-deception. Death makes man honest.

7. The realization of the death of myself leads to strength. To be strong means not to be intimidated by real or symbolic death. Having conquered these threats, man faces no others. The world of self-fulfillment belongs to the strong, decisive, and courageous man.

8. To accept death means to take charge of one's life. The man who sees the genuine function of death in life is no fatalist. He does not feel strictured. On the contrary, he is the freest of all men. Nothing holds him back but his own free decisions. He has nothing to fear, nothing to be timid about, nothing to make him feel dependent, inadequate, or inferior; he has once and for all conquered the ultimate threat.

9. The thought of death urges one to assume a total plan for life. The vitality of death leads one to adopt an ideal or goal, a noble life, or a major achievement as the purpose of existence. Through the vitality of death, one is able to see all events in life from the perspective of total existence. This enables us to perform tasks that might otherwise be boring, discouraging and senseless.

10. The thought of death enables man to laugh off vicissitudes and pains. Every man has a certain type and amount of raw material out of which he can fashion for himself a good life. The amount and quality of that material varies greatly from one human existence to another and from one situation to another. But the pliable nature of the raw material is universal. To take defeat too seriously, to be thrown off balance by disappointments, is still secretely to harbor the hope that death may not be real after all and that perhaps man was meant to be immortal but, somehow, has missed his chance.

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Koestenbaum, Peter. "The Vitality of Death" OMEGA, Vol. 2, No. 4, 1972.
Pgs. 269-71.

# MODULE IV: FAMILY DYNAMICS AND FAMILY COUNSELING

## PARTICIPANT MANUAL

DEVELOPED BY:

William L. White, M.A.

## MODULE IV: FAMILY DYNAMICS AND FAMILY COUNSELING

### Purpose and Goals

The purpose of Module IV is to orient the hospice care nurse to family centered approaches to the care of hospice patients and their families. The goals of the module are to assist the hospice nurse in:

- Understanding the impact of death upon the family system
- Assessing the resources and vulnerabilities of families involved in hospice care, and
- Developing interventions aimed at supporting the dying patient and reducing the psychological vulnerability of the patient's family members

### Module Content

The module content includes the following areas:

- The rationale for family centered hospice care
- An overview of family systems theory
- The impact of adult death on the family system
- The impact of child death on the family system
- A Family Assessment model
- A review of potential nursing goals and nursing interventions with the families of hospice patients.

### Learning Objectives

At the conclusion of Module IV, participants will be able to:

- List four advantages of family centered hospice care
- Define and discuss the following concepts
    - family system
    - nuclear family, extended family, social network
    - the family life cycle
    - the enmeshed family/the disengaged family
    - open vs. closed family systems
    - family subsystems
    - family homeostasis

  - the identified patient/scapegoating
  - family roles
  - family rules
  - fusion vs. differentiation

- Describe the impact of death on the reorganization of roles within the family system
- List two functions of scapegoating in families with a dying member
- List two beliefs (that may lead to serious emotional disorders) often held by children who have been excluded from the family mourning process
- Describe the impact of child death on the parental subsystem, the marital subsystem, and the sibling subsystem
- Recognize the replacement child syndrome
- Identify the nine categories of information contained in the family assessment model outlined in the module
- Outline major nursing goals and nursing interventions for the families of dying patients.

## Module Organization

Module IV has been divided into six content areas. Section A introduces the module and provides the rationale for family centered hospice care. In Section B, we will present an overview of family systems theory and utilize these concepts to understand the impact of adult death (Section C) and child death (Section D) on the family system. Section E will focus on family assessment techniques and in Section F we will outline nursing interventions for the more common problems experienced by families in hospice care.

## SECTION A. FAMILY CENTERED CARE OF THE DYING

During the past decade tremendous strides have been made in the development of more humane and effective methods of caring for the dying. The hospice movement, as one of the most important embodiments of improved care of the dying, has pioneered a service model that places great emphasis on the family. Where traditional care of the dying excluded the family from the care-giving process and neglected the emotional needs of family members, most hospice programs incorporate the family as an integral part of the interdisciplinary team caring for the dying patient and recognize the provision of support to family members as a crucial and essential element of hospice care. Families thus hold dual roles as providers of service to the dying patient, and recipients of emotional support services from the hospice program. In this module, we will explore how the hospice nurse can effectively relate to families in each of these roles.

Much of the material on the impact of death on family members has focused on the grief and mourning experienced by individual family members, particularly spouses. While this material (which has been reviewed in Module III) may help us understand individual grief responses, it frequently fails to address the impact of death on the constellation of relationships within the family and the impact of death on the emotional organization of the family system. It is these latter aspects that will be emphasized in Module IV.

This module is based on a number of key understandings, each of which will be fully explored. These understandings are explicitly outlined below:

- The family is the primary unit of hospice care. This implies that the total need of the family system, not just the needs of the dying patient, must be reflected in the plans for service.
- The normal equilibrium of the family is thrown painfully out of balance when one of its members becomes terminally ill and subsequently dies. In confronting this crisis, there are psychological tasks that must be completed by each family member and by the family as a unit. These tasks include the grief work of individual members, the reallignment and readjustment of family member roles, re-establishment of family routines and rituals, etc.
- Failure to complete these tasks increases the physical and psychological vulnerability of surviving family members and precipitates the progressive fragmentation of the family system.
- The death of a child poses special problems that may have a particularly disorganizing impact on the family system. These special problems must be recognized in the development of service plans for such families.
- A primary goal of hospice care should be to prevent the disintegration of the family unit confronted with the death of one of its members.

- Family intervention ideally encompasses the acute care phase of a patient's treatment, but at a minimum must begin at the time a diagnosis of terminal illness is made.

- Given the ability to be accepted in the home setting and the readily accepted role as a caregiver, the nurse can play a critical role in maintaining the health of the family in the midst of the painful loss of one of its members.

These understandings will be fully elaborated through the various sections of this module.

Family centered hospice care offers four distinct advantages to the dying patient and their family. Family centered care:

1. increases the psycho-social support available to the dying patient.
2. increases the likelihood that unstated emotional agendas (regrets, sorrows, thank-you's, resentments, expressions of affection, good-byes, etc.) can be made explicit between family members.
3. decreases the psychological casualty rate of surviving family members
4. decreases the fragmentation and disorganization of the family system that is frequently associated with a death in the family.

## SECTION B. UNDERSTANDING THE FAMILY AS A SYSTEM

Since the mid-1950's there has been an intensified effort by researchers and health and social service practitioners to better understand the phenomenon of family life. Much of this effort was spawned by the failure of individual approaches to adequately provide effective treatment approaches for severe emotional and behavioral problems. New knowledge and understandings about the nature of the family emerged from research into such severe emotional disorders as schizophrenia. The works of men and women like Bowen, Ackerman, Jackson, Haley, Satir, Minuchin, etc. began to provide entirely new ways to conceptualize the family as a dynamic system. They viewed the dysfunctional behavior of individuals as symptomatic of disruption in the family system. Such a view consequently defined the entire family system, not the symptomatic individual, as the unit to be worked with. In the following pages, we will utilize the concepts of a number of the family theorists to elucidate our understanding of the impact of death on the family system.

When we speak of family systems, we are concerned with the interrelationships, interdependencies, and reciprocity of roles within the family unit. Problems of individuals arising during crisis situations are viewed within the context of these relationships, rather than by focusing solely on the nature of individual personalities. The family unit is conceptualized as a system because it is subject to certain laws that govern systems. These laws are briefly enumerated below.

1. The family system as an entity is greater than the sum of its parts. A family system is much more than a collection of the individual personalities, attitudes, values, beliefs, etc. of those individuals making up a family. The family system is a composite of both individual family members and their multiple interactions with one another. Exhibit IV-A, for example illustrates the dyadic relationships within a four person family system.

   It can be seen that in a four person family, there are six dyadic relationships that influence the health of the total family system and the individual family members. In the family system displayed in Exhibit IV-A, there are three sets of family member needs struggling to be met simultaneously: there are the individual needs of each member, the needs in the marital relationship between the husband and wife and the needs between the parents and the children. These multiple need systems and the relationships in which they are met represent a much more dynamic picture of the family than if we viewed the family as merely the collection of individual personalities under the same roof.

2. Anything which affects the family system-as-a-whole affects each individual member of the family. Broad social and economic conditions e.g., inflation, unemployment, discrimination, neighborhood disorganization, etc. that effect the family as a unit have equal effects on each individual within the family.

3. Any change in one member of the family unit affects all other members individually and the system-as-a-whole. If one member of the family leaves, changes their role or level of participation in the family, or undergoes a personal crisis; other members of the family will be forced to change also. This particular tenant of systems theory is particularly important. We will contend throughout this module that the chronic illness and death of a family member has a direct impact on every other family member and forces the need for reorganization of the family system-as-a-whole.

Systems theory conceptualizes the family at three levels: the nuclear family, the extended family, and the social network. The nuclear family, which will receive greatest emphasis in this module, generally refers to

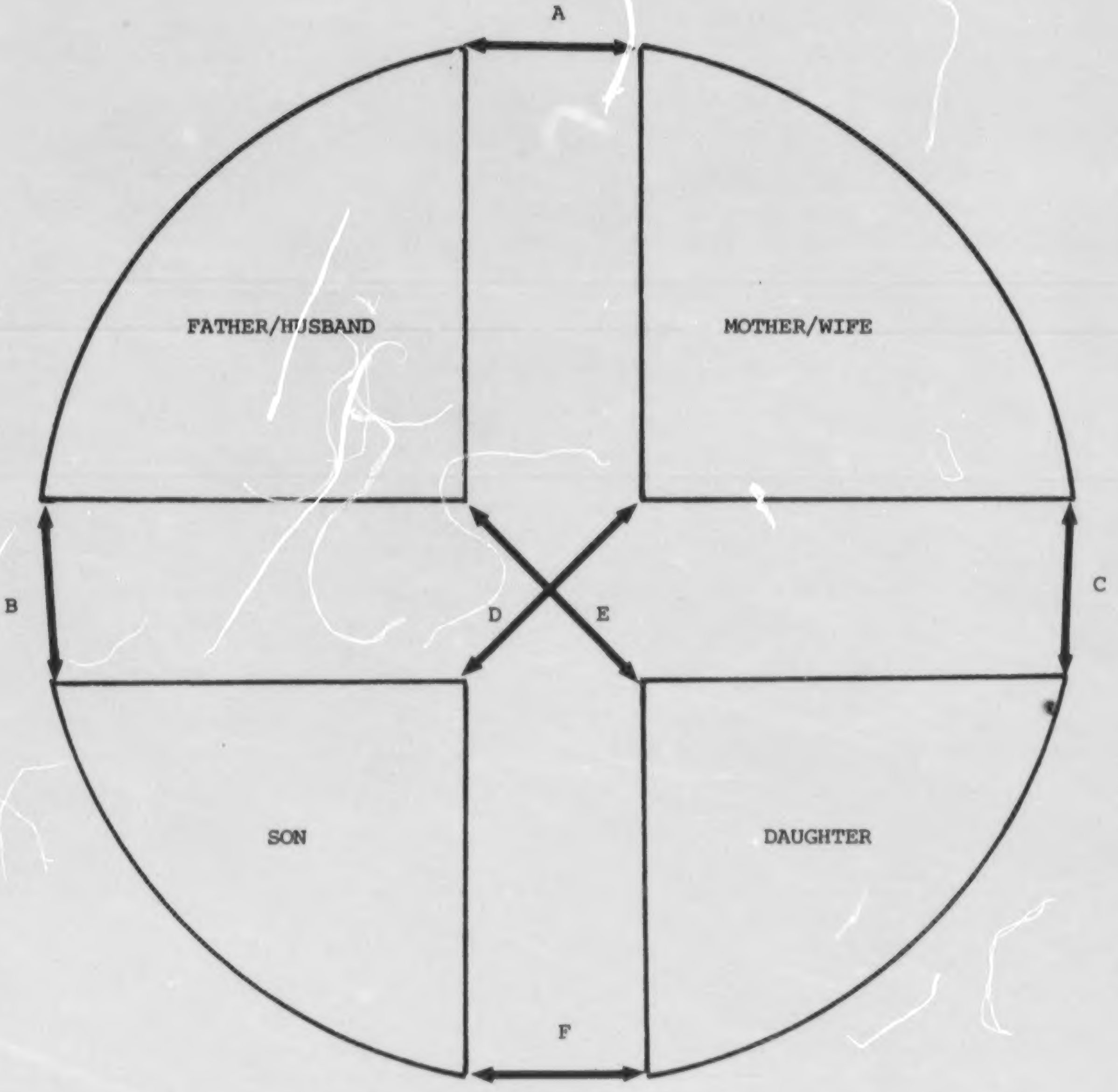

A
FATHER/HUSBAND
MOTHER/WIFE
B
C
D
E
SON
DAUGHTER
F

EXHIBIT IV-A: DYADIC FAMILY RELATIONSHIPS IN A FOUR PERSON NUCLEAR FAMILY

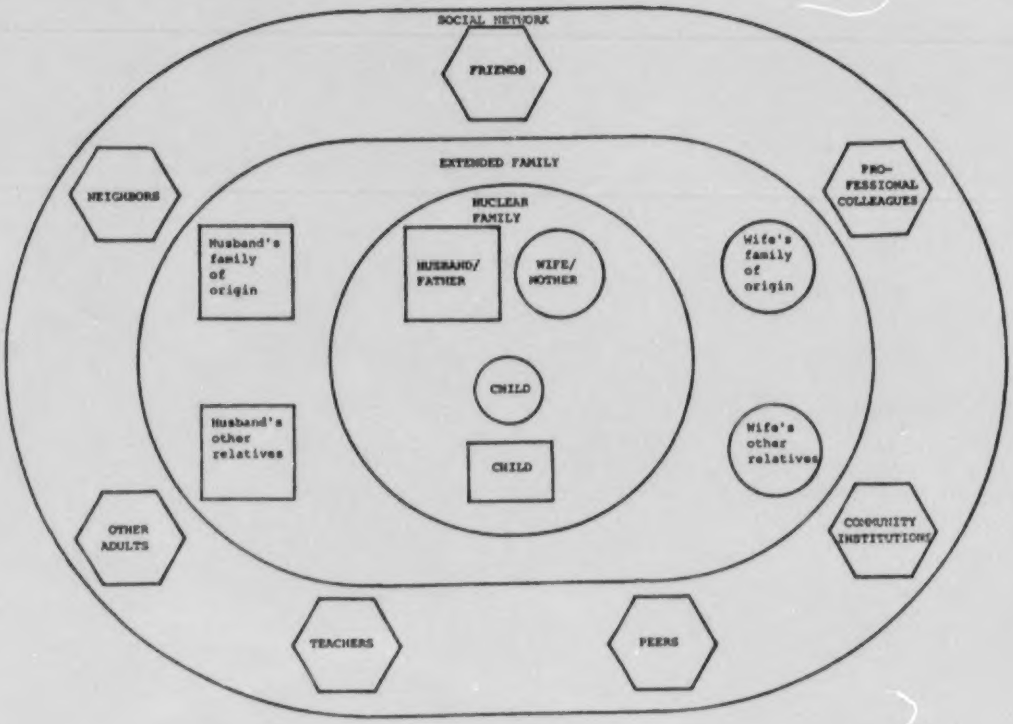
that stable group of people who live together. The nuclear family is different than the "family of origin" which is a phrase used by family theorists to refer to the nuclear family from which a particular person came. The extended family refers to the nuclear family's relationships with the families of origin of both the husband and wife. The social network refers to the friends, neighbors, co-workers and other significant persons in the lives of nuclear family members. These various levels of the family system are graphically displayed in Exhibit IV-B.

## The Family Life Cycle

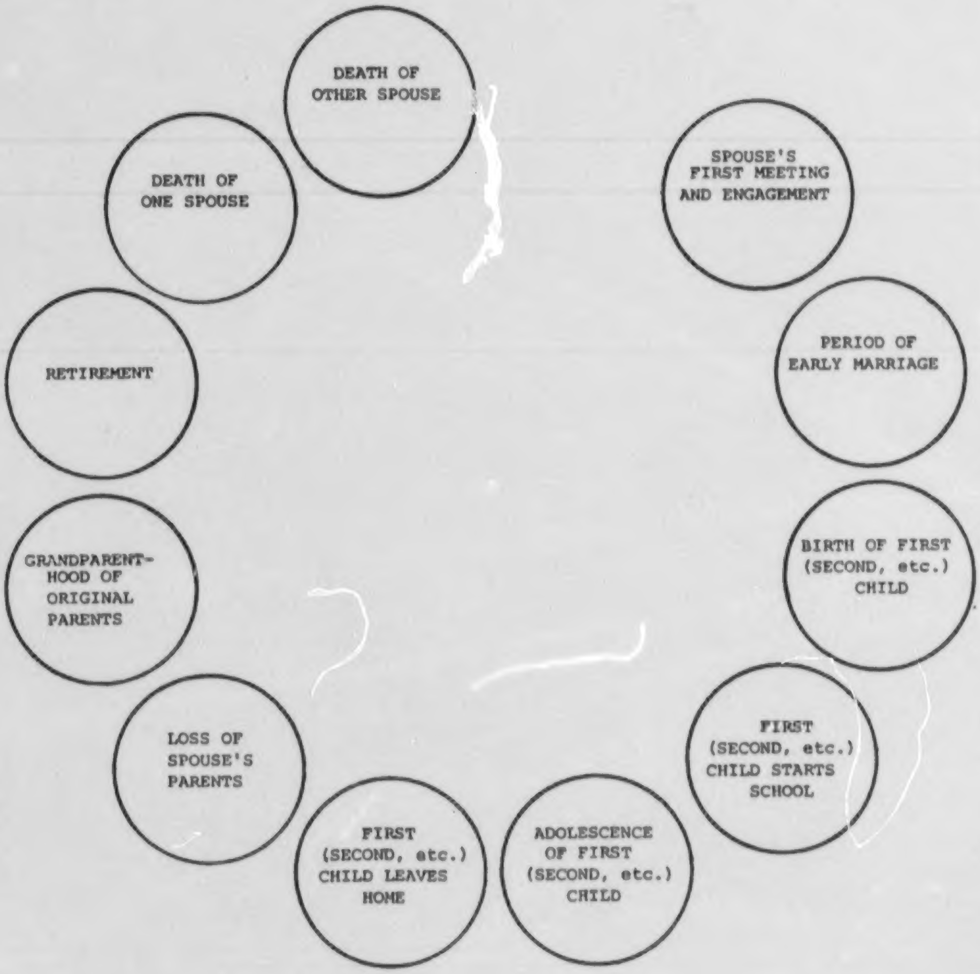
Families, like individuals, go through various developmental stages that are often referred to as life cycles. Family theorists have spent a considerable amount of time trying to conceptualize these life cycles. Exhibit IV-C illustrates one common family pattern. These chronological stages differ greatly from family to family. Some families skip stages or repeat the same stage several times.

Irregardless of the differences between families, it is clear that major crises within the family system often occur in the transition from one developmental stage to another. These transition periods usually require a major redefinition of the roles and status of family members. The birth of the first child, for example, requires a delineation of parental roles and responsibilities and is often accompanied by significant changes in the marital relationship. Other events, such as serious illness or injury, death, unemployment, geographical relocations, etc., may occur that further exacerbate the family's transition from one developmental stage to another.

## EXHIBIT IV-B: A FAMILY SYSTEM: NUCLEAR, EXTENDED AND SOCIAL NETWORK


SOCIAL NETWORK
FRIENDS
NEIGHBORS
PRO-FESSIONAL COLLEAGUES
EXTENDED FAMILY
NUCLEAR FAMILY
Husband's family of origin
HUSBAND/ FATHER
WIFE/ MOTHER
Wife's family of origin
CHILD
Husband's other relatives
CHILD
Wife's other relatives
OTHER ADULTS
COMMUNITY INSTITUTIONS
TEACHERS
PEERS

## EXHIBIT IV-C: EXAMPLE OF FAMILY LIFE CYCLES


DEATH OF OTHER SPOUSE
SPOUSE'S FIRST MEETING AND ENGAGEMENT
PERIOD OF EARLY MARRIAGE
BIRTH OF FIRST (SECOND, etc.) CHILD
FIRST (SECOND, etc.) CHILD STARTS SCHOOL
ADOLESCENCE OF FIRST (SECOND, etc.) CHILD
FIRST (SECOND, etc.) CHILD LEAVES HOME
LOSS OF SPOUSE'S PARENTS
GRANDPARENT-HOOD OF ORIGINAL PARENTS
RETIREMENT
DEATH OF ONE SPOUSE

Describe the current developmental stage of your family of origin.

____________________________________________________________

____________________________________________________________

____________________________________________________________

Describe the current developmental stage of your nuclear family.

____________________________________________________________

____________________________________________________________

____________________________________________________________

The impact of serious illness and death upon the family system is influenced greatly by the particular developmental stage of the family. Think of a recent family you were involved with in the hospice program.

What developmental stage was this family experiencing?

____________________________________________________________

How did this developmental stage influence the family's response to the impending death or death of the family member?

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

## The Changing Nature of the Family

It has probably already occurred to the reader that the descriptions of the nuclear family and the family life cycles need significant expansion to encompass the rapid changes that have occurred in the very nature of the family in our culture. These changes raise a number of important issues and implications for our work with dying patients. Consider the following.

- The rising rate of marital separations and divorce has resulted in a dramatic increase in the number of one parent families. What particular problems occur and what particular supports are needed when a member of this type of family is dying?
- An increasing number of families who have experienced divorce also experience remarriage and the blending of two family units. How do

we approach involving multiple families (e.g., ex-spouses, children from previous marriages, step children, children from current marriage, current spouses, ex-in laws, current in laws, etc.) in a coordinated plan of hospice care?

- There is increasing diversity in patterns of family life and family life cycles. An increasing number of married couples are choosing not to have children. Increasing numbers of people are living together as unmarried couples or in group living situations. There is increased incidence or at least visibility of homosexual relationships. What implications do these changes in family life and changes in the traditional pattern of intimate relationships have on the provision of family centered hospice care?

As we proceed through the module, try to reflect on how the material and concepts apply to those families and relationships that are not what we are most accustomed to. The written material will present concepts and approaches that fit the most frequently experienced families in the hospice programs. It will be important in our discussions and learning exercises to explore the special issues, concerns, and problems that make up the exceptions to these experiences.

## Ethnic, Cultural and Religious Influences on Family Organization

It is significantly beyond the scope of this module to address all of the ethnic, cultural, and religious influences on family organization and the roles and rituals utilized by families to approach death. It is hoped that the reader recognizes the importance of understanding such influences as a most essential prerequisite to providing family centered hospice care. Nurses working in hospice programs that serve very heterogenous patient populations are urged to seek more advanced training and workshops that will help them develop greater ethnic, cultural, and religious sensitivity in providing care to families.

## Family Types

Families can be categorized by the degree of dependency between family members and by the nature of the family's relationship with the outside world. Each of these factors influences the family's response to the death of a family member. Minuchin (1967) developed a continuum of family types that included:

- The enmeshed family

- The disengaged family
- The normal family

The enmeshed family is characterized by a "tight interlocking" of family members. There is a high degree of mutual dependency between family members and minimal boundaries between members of generations. In the enmeshed family, there is too much closeness and involvement between family members and little differentiation between members. Enmeshed families maintain strong boundaries between the family and the outside world. These families are so extremely close knit and have such a high degree of emotional symbiosis that the illness, and particularly the chronic and terminal illness, of one member has a profound impact on other members and the overall relationships in the family system. The identity and self-esteem of individuals in enmeshed families are so closely tied to other family members that the threatened loss of a member increases the emotional vulnerability of all members of the family. It is in the enmeshed family that the death of a family member may often precipitate multiple health and emotional problems among surviving members.

Think of an enmeshed family that you have worked with. Describe the impact of illness and death on the individual members and the family relationships.

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

The disengaged family represents the other end of the continuum of family types. In the disengaged family, there appears to be an absence of structure, order, or authority, and bonds between members are weak or nonexistent. There is little mutual dependence in the disengaged family, although there may be strong boundaries between the family and the outside world.

Think of a disengaged family you have worked with. Describe the impact of illness and death on the individual members and the family relationships.

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

The "normal family" represents the midrange on the continuum between enmeshment and disengagement. In the normal family the identities of individual members are maintained without either excessive dependence or isolation. There is in the normal family a flexability, lacking in enmeshed and disengaged families, that allows the family to increase or loosen bonds between members based on the needs of individual members and the total family system.

Think of a family you have worked with that falls within the normal range. How did this family's adjustment to illness and death differ from that of the enmeshed and disengaged families you described earlier?

______________________________________________________________

______________________________________________________________

______________________________________________________________

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______________________________________________________________

______________________________________________________________

Satir (1972) has outlined another model of looking at families that focuses on the nature of family communications, family rules, and the family's relationship with the outside world. Satir describes families as open or closed systems. Closed family systems are characterized by:

- An extreme resistance to change,

- Restriction of transactions outside the family (similar to the strong "boundary" described by Minuchin)
- Indirect, unclear, and unspecific communication
- Covert, out of date rules governing family behavior
- Prohibitions on communicating or commenting about family rules and beliefs

Open family systems, on the other hand, are characterized by:

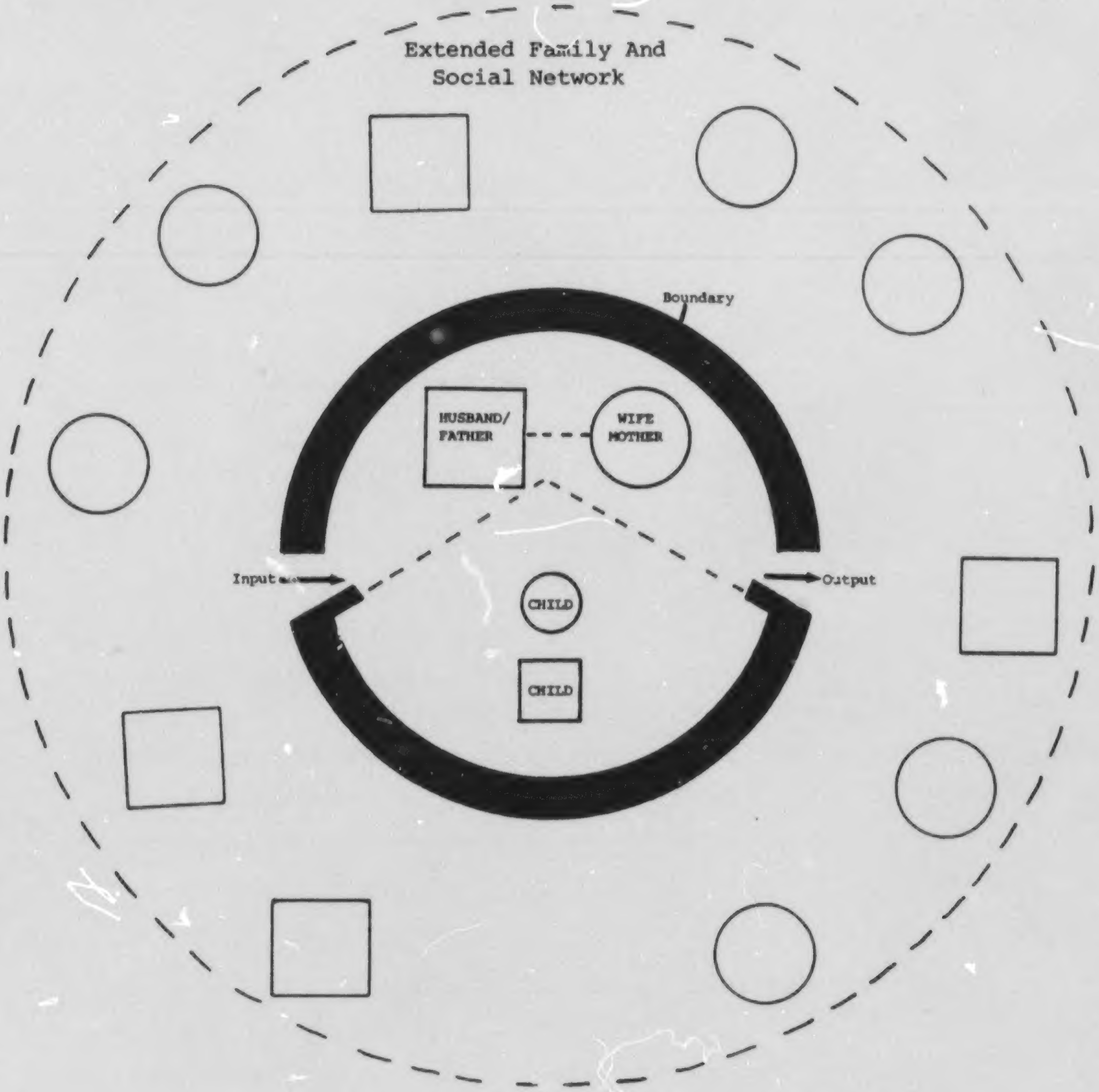
- Change being viewed as inevitable and normal
- Direct access to supportive relationships outside the family
- Direct, clear, and specific communication
- Flexible and changing rules governing family behavior that meet the needs of individual members
- Permission within the family to communicate and comment on family rules and beliefs.

If we look at Exhibit IV-D, we can see a nuclear family surrounded by the extended family and social network. The line that separates the family from the outside world is called a boundary. Closed family systems have very rigid boundaries making it very difficult for family members to have contact/relationships outside the nuclear family (output) and making it very difficult for persons outside to make contact with family members (input). Open family systems have very permeable boundaries allowing both family members and outsiders easy transactions across the boundary. The relative openness or closure of the family system is usually determined by the father and/or the mother. They, in essence, determine who and under what conditions persons will have contact inside or outside the system.

The relative openness or closure of the family system will influcence:

- The families ability to provide care and emotional support to the dying member
- The ability of the family to adjust to the changes precipitated by the death of the family member
- The families willingness to accept help and support from someone outside the family.

## EXHIBIT IV-D: OPEN VS. CLOSED FAMILY SYSTEMS


Extended Family And
Social Network
Boundary
HUSBAND/
FATHER
WIFE
MOTHER
Input
Output
CHILD
CHILD

Of the family typologies presented, the enmeshed family described by Minuchin and the closed family system described by Satir have a high potential for severe family disruption and the severe emotional dysfunction of individuals precipitated by illness and death of a family member. The isolation of family members from outside support, the high level of interdependence between family members, the rigid resistance to change, and the communication problems in these families makes the experience of death extremely disruptive to individuals and the family system as a whole. Nursing interventions with these types of families will be explored in Section F of this module.

## Family System Characteristics

### Family Subsystems

To understand the impact of illness and death on the family, it is important to look at the nature of the subsystems that exist within the family. The following are some of the subsystems that exist within families.

- Dyads - the special relationship that exists between any two family members, e.g., mother/father, mother/son, etc. Figure IV-A illustrated the potentially six family dyads in a four person family.

- Coalitions - two or more family members with a special bond or alliance that is different from other relationships within the system; for example, two male members, father and son, versus the rest of the family (mother, daughter, and another son) or children versus parents. Coalitions may change from moment to moment; for example, the male members may unite to watch a particular television program or father and daughter may take on mother and son in an argument.

- Triangles - three person configurations that are the basic building blocks for most emotional systems. Triangles are formed to help address emotional energy, conflict, tension, etc. in relationship dyads. A two person system can be stable as long as it is calm, but when anxiety increases, it immediately involves the most vulnerable person to become a triangle, e.g., two siblings fighting, involving the mother or father. In addition to the above, Otto Pollack (1964) has outlined a model of three subsystems within the family: the marital relationship, the parent-child relationship, and the sibling relationship. These three subsystems are highly interrelated so that a deterioration in one area is likely to bring deterioration in the other two.

We will see in sections C & D how the death of a parent or child disrupts all of the above emotional configurations.

## Family Homeostasis

Family homeostasis refers to the inherent tendency of family systems to maintain their balance or equilibrium. To maintain such equilibrium or stability, most families have developed roles, rules, and patterns of repetative behavior that tend to create a high level of predictability and security for family members. Such repetitive patterns, even when destructive, often continue in spite of the best efforts of the family and the family therapists to change them. When a family member dies, the equilibrium of the family system is thrown out of balance and the major emotional energy of the family is directed toward re-establishing that balance in the absence of the lost member. The provision of support to the family is particularly important when we consider that the patterns of family behavior established following the death (the re-establishment of homeostasis) may govern the health or disturbance within the family for years to come.

## Identified Patient (Scapegoat)

The identified patient is a term that refers to that family member who symptomatically expresses the conflict and disruption in the family system. The scapegoating of a family member is a common family process that serves to provide greater cohesion and unity in order to insure the survival of the family. The most common manifestation of this scapegoating process is the child or adolescent who becomes the identified patient in response to intense marital conflict. Scapegoating can also serve to provide an important diversion and aid in the family's denial of the impending death of one of its members. Consider the following scenario.

> The G. family, consisting of mother, father, 14 year old son, and 12 year old daughter, came to a family service agency with the presenting problem of the acting out behavior of the adolescent son. The son during the past six weeks had been skipping school, drinking, committing minor acts of vandalism, and on two occasions had stayed out overnight without permission. The family was quite concerned about the son and appeared to be spending the majority of their emotional energy trying to respond to his behavior. During the second visit, reference was made of "dad's condition" by the 12 year old daughter, and with further probing it was revealed that Mr. G. had been recently diagnosed with cancer and given nine months to live. At that time the children were told and

> it was agreed that the family would continue to live just like it had (meaning that the approaching death was not to be talked about in any way). The tension produced by this pact of silence was almost more than any of the family could bear but was soon relieved by the growing concern over the behavior of the son. Over the next several sessions, the focus shifted from the son to the family's preparation for the death of the father. The symptomatic behavior of the son ceased at the point the family began to directly confront the approaching death.

This case classically illustrates how one family member's symptomatic behavior can divert the emotional energy of the family away from a much more painful and threatening issue. The acting out behavior of the adolescent son served effectively to mask the anticipatory grief of all family members and protect the denial of impending death within the family system.

Family Roles

Each family member may have many roles within the family. For example, a woman may fulfill such roles as mother, wife, career woman, disciplinarian, pal, peacemaker, etc. Family members are sometimes assigned roles before birth. Children's roles often depend on such factors as birth order, sex, energy level, and the circumstances in the family surrounding the child's birth.

List the roles you perform in your family.

______________________ ______________________

______________________ ______________________

______________________ ______________________

______________________ ______________________

The development of roles is an ongoing process throughout our lives. Our own personal growth and changes within our families require taking on new and different roles. In healthy families, roles are highly flexible and one member may take on the roles of another. For example, a mother may take on the roles of the father who is injured, ill, or not able to perform his normal functions in the family. In troubled families, roles are highly rigid and members have great difficulty interchanging roles or taking over the roles of a family member who for whatever reason cannot continue to perform their role functions.

An understanding of family roles is very important to the hospice nurse. First, the roles performed by the dying patient in the family and the family's ability to absorb these roles by other family members have a profound impact upon the family's overall response to the patient's death. Second, the nurse can play an important part in helping families redefine roles following the death of a family member. Both of these points will be further explored in later sections of the module.

## Family Rules

Satir (1967, 1972) has explored the nature of both the spoken and unspoken rules that govern fanily life. Each family has its own unique rules that govern how we act, what we can feel, what we can express, and what kind of relationships we can have with others. Such rules have often been passed down from generation to generation and have not been examined for their origin or for their current utility for the family. Family rules may cover many diverse aspects of individual and family life. Examples of family rules might include:

- Don't raise your voice
- Men cannot be trusted
- Make others happy
- Daddy works hard. His needs are more important than ours
- You can be anything you want to be
- Go to college
- Don't talk about __________'s illness
- Anger and hate are the same thing
- If you aren't careful, you'll end up just like . . .
- Sex--don't talk about it or enjoy it; if we're quiet, maybe it will go away
- Children must be protected from painful experiences, e.g., funerals
- A woman's place is . . .

- Children should be seen and not heard
- Don't cry or I'll give you something to cry about
- Marry early (or late)
- Feelings are important
- We can work it out
- You should be ashamed of yourself
- To ask for what I want is selfish
- Take care of everybody
- Never make mistakes
- Everybody must agree
- We know what's best for you
- You are a special person
- Stay married at all costs

In healthy families, rules are openly stated and negotiable. In troubled families, rules governing behavior are often more hidden and there are prohibitions against making such rules explicit or trying to negotiate them.

As the hospice nurse works with dying patients and their families, a number of family rules may pose obstacles to the resolution of grief and the re-stabilization of the family following the death. Such rules may include proscriptions for family member roles, specific rules on the appropriate response to death, and more general rules governing the expression of emotion within the family. Identify rules you have observed in families that posed major difficulties in the family's adjustment to the death of a family member.

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## Fusion vs. Differentiation

The last family characteristic we will examine is the degree of autonomy that exists among family members. Murray Bowen has explored this aspect of family dynamics and posits that a family member can best be understood in terms of their degree of differentiation from or fusion with other family members. Bowen's concepts of "fusion" is related to Minuchin's concept of "enmeshment" described earlier. Where enmeshment describes the closure of the family system and the overinvolvement between members in the entire family system, fusion refers to the lack of identity and separateness of individual family members. When one family member experiences fusion with another family member, an extremely symbiotic relationship exists that in essence says: "I cannot live without you; I have no independent existence." When one individual is fused to another, the person's emotional security and identity is tied directly to the person with whom they are fused.

The degree of fusion between individual family members and the dying person has important repercussions on the future health of family members and the stability of the family system. One could speculate, for example, that the high mortality rate of widows and widowers following the death of their spouses, may be closely related to the high degree of fusion between themselves and their spouses.

In this section, we have conceptualized the family as a dynamic system and outlined a number of terms and concepts to increase our understanding of the manner in which family systems operate. In the next two sections, we will utilize these concepts to understand the impact of death on the family system.

## SECTION C. THE IMPACT OF ADULT DEATH ON THE FAMILY SYSTEM

There exists an extensive body of literature on the impact of death upon surviving individuals. There is, however, much less known about the impact of death upon the family as a system. In this section, we will try to overview what can occur within the family system in response to life threatening illness and the death of a family member.

Module III outlined in detail the individual processes of grief and mourning involved in the loss of a loved one. These reactions, when viewed within the context of the family system, have a multiplier effect. That is to say that the impact of death on the family is greater than individual reactions of family members. The grief reactions of each member in turn effects the reactions of the other family members. Grief is not an isolated intrapsychic process, but takes shape within the network of relationships within the family system. The mechanisms for family homeostasis mentioned earlier continue to operate during the crisis of loss to maintain the emotional balance of the family. The extreme and disabling grief reactions of one family member are offset by one or more other members being the "strong ones" who complete tasks essential for the survival of the family as a unit. In this case, the dysfunction of one family member is balanced by the over-functioning of other members. The recognition of such balances is the beginning point for working with bereaved families.

We noted earlier that each family member has a number of roles that they play within the family. These roles and the nature in which they complement each other contribute to the emotional stability of the family and add a high degree of predictability to the daily life of the family. The impairment of a family member's roles (due to illness) and the loss of those roles (due to death) disrupts the balance of roles in the family and eliminates the element of predictability. The loss of a family member requires a change and reorganization in roles of all other family members. This reorganization of roles may be extremely disruptive to family relationships, particularly in families where roles have been very rigidly defined.

The emotional vulnerability of the bereaved family is related to (Hollingsworth, 1978; MacVicar and Archbald, 1976):

- The number and type of roles held by the family member
- The ability of family members to perform tasks essential for the continuity of family life
- The ability of individual family members to adjust their personal goals and maintain their self-esteem

- The resources available to the family, and
- The family's prior experience with crises that required role adaptation.

The demand for family role reorganization precipitated by illness and death can be further illustrated with the following case history.

The B Family consisted of Mr. B., age 40; Mrs. B, age 41; a daughter, Gloria, age 16; and a son, Michael, age 13. Mrs. B died less than a year following her diagnosis of cancer. Prior to Mrs. B's illness and death, the family could be described as follows.

The B family could be considered a relatively normal middle class family. Mr. B. had worked as a carpenter all of his adult life and Mrs. B worked the five years preceding her illness at a small flower shop. Both paternal and maternal grandparents were living, although they lived a great distance from the B Family. The family had not experienced the death of anyone close to the family nor any other type of emotional crisis that required major role changes in the family. The family could easily be described as "close knit" and although the B Family had a large number of friends, socializing with others was secondary to family centered activities.

The family relationship dyads could be briefly described as follows:

Mother-Father. Mr. and Mrs. B were high school sweethearts and married upon Mr. B's return from military service. They had maintained a close and affectionate relationship throughout their marriage. Their major conflict had come over the amount of freedom that should be given their 16 year old daughter. Mrs. B was usually able to mellow the very restrictive stance preferred by Mr. B. Mr. B. could be described as a real "family man" spending most of his time at home and getting most of his emotional needs met through Mrs. B. Mr. B. spent most of his time remodeling the homes they lived in, leaving most disciplinary matters, financial affairs, social events, home upkeep, etc. to Mrs. B.

Mother-Son. Mrs. B spent a good deal of time talking to her son, who found he could do things with his dad but had difficulty talking to him. Mrs. B and Michael spent most of their time talking about school, Michael's ever changing friends, and the inevitable teasing and fighting between

Michael and his older sister.

Mother-Daughter. Mrs. B had an extremely close relationship with Gloria, her 16 year old daughter. Gloria spent considerable time talking with Mrs. B about boyfriend problems and her future plans for college. Mrs. B also was actively supportive of Gloria's interests and activities in gymnastics and swimming.

Father-Son. Mr. B and Michael were very active together, e.g., fishing, working on their house, attending baseball games, etc. Mr. and Mrs. B had divided their emotional investment in the children with Mr. B spending most of his time with Michael and very little time with Gloria. Mr. B hoped Michael would show an interest in carpentry and that he would eventually join Mr. B's business.

Father-Daughter. Mr. B had increasing difficulty understanding and relating to his daughter, Gloria. He could not understand Gloria's desire to spend so much time away from home, her preoccupation with boys, and her incessant demands to do all the things her friend's parents allowed them to do. He and Gloria inevitably ended up in arguments when they talked, which usually ended with Mrs. B intervening to make peace.

Daughter-Son. Gloria and Michael were at an age when they considered each other a "nuisance." Michael teased Gloria constantly about her boyfriends and did everything possible to embarass her when her boyfriends were visiting. Gloria, for her part, regularly pointed out Michael's inability to make friends and his intolerably "childish" behavior.

In briefly reviewing this family, we find Mrs. B at the emotional center of the network of relationships, and the primary organizer of family life. The numerous roles she performs in the family included:

- Wife
- Mother
- Sexual partner
- Career woman (35% of family income)
- Cook

- Housekeeper
- Confidante/counselor to husband (work problems) and daughter (school, relationship problems)
- Chauffeur
- Peacemaker--conflict between father and daughter, and daughter and son
- Organizer of family social activities
- Manager of financial affairs
- Disciplinarian

Describe the role changes you would anticipate in each of the following family members following the death of Mrs. B:

Mr. B: ____________________
____________________
____________________
____________________

Gloria: ____________________
____________________
____________________
____________________

Michael: ____________________
____________________
____________________
____________________

What changes or problems would you anticipate in the following relationships following the death of Mrs. B?

Mr. B--Relationships outside the family:

____________________

____________________

____________________

____________________

Mr. B--Gloria:

____________________

____________________

____________________

____________________

Mr. B--Michael:

____________________

____________________

____________________

____________________

How might the hospice nurse help a family such as the B family complete reorganization of family roles?

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Family role reorganization does not begin at the point of death. It often begins early in the illness and extends months and sometimes years after the death of the family member. During the course of the illness, various roles of the dying family member cease or are progressively impaired. Part of the anticipatory grief of family members is the actual mourning of the loss of these roles performed historically by the patient in the family.

Think of a family that you have worked with in your hospice program. What roles did the patient perform within the family?

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________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

What adjustments were made in the roles of other family members following the patient's death?

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________________________________________________________________________

## Redefinition of Family Rules

In addition to the reorganization of family roles, the rules that have regulated family behavior may come under serious questioning following the death of a family member. In some families, for example, when a very authoritarian parent has died, family rules may be renegotiated and become much more flexible and responsive to the current needs of family members. In other families, the deceased member may be maintained as a "ghost" within the family with the old rules rigidly adhered to. This latter example represents an extreme form of denial in which the family system continues to operate as if the deceased is still in the family, e.g., "you know your father (who is deceased) doesn't approve of that."

Old family roles may not apply to the new realities created by the loss of a family member. Families rules against the open expression of emotion may handicap the efforts of the family to mourn the loss of one of their members. Family prohibitions against accepting charity may not be congruent with the economic realities following the death of a parent who was the sole financial supporter of the family. In short, death forces the family to reassess the rules that govern the family. The examination of such rules, that may have governed the family for decades and in some cases for generations, is a very unsettling process that often requires the support and perspective of someone outside the family, e.g., the hospice nurse.

## Scapegoating

In section B, we cited a case example of how scapegoating can occur in the family system to divert the family's attention away from the approaching death of a family member. In addition to denial, scapegoating can also be used to avoid expressing resentments against the dying person.

> Mr. G was diagnosed with cancer and given six months to live by his physician. From the time he was diagnosed, Mr. G cut off nearly all of his social relationships, stopped performing all of his normal family responsibilities, became increasingly dependent and abusive to his wife and children. His excessive and impulsive demands upon family members (he called the family together at least twice a week to say his final goodbyes) and the fact that he lived much longer than the physician's projection had almost completely drained the family emotionally. A major portion of the family energy, however, focused not on the resentments at the father but at the behavior of one of the sons who had told his father to "stop whining and die like a man." The family was shocked by this behavior and spent a great deal of time condemming the son for taking a stance with his father that most other members secretely envied. The preoccupation with, and ostracism of the son served to prevent direct resentments against the father from being communicated by other family members.

Such scapegoating prevents the direct expression of emotion within the family system and is often as destructive to other family members as it is to the person scapegoated.

## Enmeshed and Fused Relationships

In section B we described both family network and dyadic family relationships that had become extremely symbiotic as expressed in the phrase, "I have no identity or existence separate from you." Death has a devestating impact upon enmeshed families and fused relationships. In the former, the isolation of the family system and the overconnectedness between members makes the loss of a member particularly disruptive. Death in a fused relationship leads to the desire of the surviving members to join the deceased e.g., suicidal thinking, giving up one's will to live, etc. It is quite possible that such cases of overdependency make up a significant portion of those widows and widowers having high morbidity and mortality rates following the death of a spouse.

## Changing Intimacy Patterns

Death disrupts the emotional alliances within the family and effects the ability of some bereaved members to tolerate intimacy and closeness with others. The crisis precipitated by the death of a family member may create close emotional alliances where none existed and lead to the fragmentation of other previously close relationships. Family members of a dying patient frequently avoid emotional contact with one another to the detriment of the whole family and some members may develop a pattern of emotional distancing that will effect their relationships for years to come.

> Mrs. P was a married woman in her late twenties who had had no direct experience with death. Within an eighteen month period, her best friend, mother, grandmother, and grandfather all died from acute or chronic illnesses. The "emotional shock wave" experienced as a result of these events led to her emotional insulation, the separation and subsequent divorce from her husband, her inability to tolerate close friendships, and her continued preoccupation with the health of her child. Her emotional experience had, in essence, been "Anyone that I care about will die."

While the multiple losses in such a short period of time is not typical, the case does provide some insight into the strains on a marital relationship precipitated by the death of one of the spouse's parents.

## Children's Response to Adult Death

The death of a parent or other significant adult, e.g., grandparents, uncles, aunts, etc. has important emotional repercussions on the sibling subsystem of the family. The nature of such repercussions appear to be closely related to the manner in which children are involved or excluded from the family mourning process.

Kubler-Ross (1974) has referred to children as the "forgotten ones" in the family mourning process. The "protection" of children by their exclusion from the mourning process, e.g., attendance at funerals, discussions of illness and death, etc. prevents the child from grieving openly and may lead to very distorted ideas of illness and death. The child's grief may get turned inward and leave the child particularly vulnerable to physical and emotional dysfunction.

The magical thinking of the child, when not countered by reality testing with adults, may leave a child:

- Believing that their anger and impulsive wish that the deceased would die, actually killed them
- Owning the personal responsibility for the death, and
- Fearing retribution (I will get sick and die, too) (Cardarelle, 1975)

Such beliefs and fears may lead to the child's isolation with the family system and the eventual development of behavioral and emotional symptoms, e.g., enuresis, nightmares, preoccupation with illness, school phobia, school adjustment problems, etc.

### Adult Death and the Social Network

So far in Module IV, we have focused primarily on the nuclear family system. Before proceding to a review of the impact of child death on the family system, it is important to add a few brief comments on the impact of adult death on members of the social network.

When we think of family oriented hospice care and the provision of bereavement counseling, we ordinarily think of providing such care to members of the nuclear and extended family of the dying patient. An increasing number of hospice programs are recognizing the importance of including significant members from the social network of the patient in this caregiving process. Such persons provide important sources of support to the dying patient and family members and may often experience grief very similar to family members but be excluded from many of the rituals and sources of support that would help them resolve such grief.

## SECTION D. THE IMPACT OF CHILD DEATH ON THE FAMILY SYSTEM

The death of a child has a particularly devestating impact upon the family system and surviving family members. Studies have shown that in families experiencing the death of a child, as many as fifty per cent of family members react to the death strongly enough to require psychiatric help (Binger, et. al. 1969). In this section, we will explore the severity and nature of the impact of child death on the family system. To provide a framework for this discussion, we have utilized Pollack's model of family subsystems (the parental subsystem, the marital subsystem, and the sibling subsystem).

Module III outlined in detail our current knowledge of grief and mourning. We will not repeat that material here, but it should be recognized that each family member's individual response to the death of a child greatly influences the relationship problems outlined below.

## The Parental Subsystem

The emotional world of the parents is in turmoil throughout the initial diagnosis, illness, death, and post death periods. A fatal disease of a child that entails a number of remissions and relapses, e.g., leukemia, Hodgkin's Disease, etc. has a particularly strong emotional impact upon the parents. Throughout these various periods, parents can be expected to display a wide range of anticipatory and subsequent grief reactions, including denial, intellectualization, irritability, depression, somatization, frenzied activity, sleep and apetite disorders, etc.

Guilt is perhaps one of the most predominant emotions experienced by parents following the terminal diagnosis of their child. There is an inevitable feeling that the parents are somehow responsible or should have been able to protect their child from such a tragedy. Some parents question whether the illness is a punishment from God. The guilt of parents may be even more intense if the child is dying from an heredity disease. Koop (1969) has observed:

> "There are few family situations more pitiful than the silent father with obvious Von Recklinghausen's disease whose child is dying of neurofibrosarcoma in the presence of the same malady. His guilt about his child's condition and his self-reproach before his wife can frequently be talked out satisfactorily, so that these problems are not added to the impending grief of the loss of the child."

Guilt can permeate the parental relationship and create a tone of self reproach and mutual recriminations that seriously effects the ability of the spouses to effectively parent the dying child and other siblings. This guilt and conflict engendered by it can also prevent the parents from providing emotional support to one another at the precise time that such support is needed most.

There is an inevitable change in the parent-child relationships produced by the terminal illness of a child. Parents can easily become overly protective and indulgent resulting in the increased dependency and regression of the sick child. The individual needs of the parents and the needs of other siblings may also be neglected as the family's emotional resources are concentrated on the ill child.

The impaired grief of the parents can also have serious consequences to the emotional reorganization of the family following the death of a child. Pozananski (1972) has described what he calls the "replacement child syndrome in which a child is used by the parents as a substitute for a sibling who has died. In most cases, one of the surviving children is selected to play the role of the deceased. A couple choosing to have another child or adoption or fostering may serve a similar purpose. The dynamics of this syndrome include:

- The idealization of the dead child
- The maintenance of the home as a shrine filled with images of the dead child
- An exaggerated concern of the parents regarding illness and accidents
- The over-protection of the replacement child
- Projection of the parents' hopes and aspirations for the deceased child onto the replacement child

The selection of a replacement child and the inability to allow the sibling to develop an identity separate from the deceased child emerges from the parents continued efforts to deny the death of their child.

Krell and Robkin (1979) have described three styles of sibling survivalhood that are shaped by the grief reactions of the parents to the death of the child. The "haunted child" is one who has been excluded from the facts and emotions surrounding the death of his or her sibling. There is a wall of silence that is maintained by the parents that creates an atmosphere of guilt and mystery for the surviving child. The haunted child is plagued by his belief that the parents feel he or she is responsible for the death and by a nighmarish fantasy that at any time the child will get sick and die too. The "bound child" is a surviving sibling who has been given a special ("preciousness of the survivor") status by the parents. The bound child is overprotected and all attempts at autonomous development are discouraged. The bound child is never intended to leave home. The "Resurrected Child" is, like Pozanski's replacement child, related to as two person--themselves and the deceased child reincarnated.

## The Marital Subsystem

Persons working with bereaved families in which a child has died have frequently observed the high frequency of marital separation and divorce following the death of a child. The reasons for this high casualty rate in marital relationships are open to speculation but may include the following.

- The emotional crisis of the illness and death of a child may increase pre-existing conflicts in a marriage beyond tolerable limits
- Separation and divorce may serve to allow the spouses to escape the continuing confrontation with the death of their child. As one man put it after his marriage had dissolved following the death of his son, "Every time I looked at my wife, I saw the face of my dead son."
- The differences in the emotional responses of the spouses to the illness of the child, e.g., overinvolvement of the mother--detachment of the father, may be a particular source of conflict and give rise to irreconcilable resentments following the death of the child.
- The grief that each spouse experiences makes it difficult to offer support to the other, reducing the ability of the marital relationship to provide replenishment from the pain of loss.
- The physical and emotional exhaustion of the parents caused by what may have been a prolonged illness and death of their child may leave both husband and wife without the emotional energy needed to sustain the relationship.

What other factors do you feel contribute to the high incidence of marital separation and divorce following the death of a child?

________________________________________

________________________________________

________________________________________

## The Sibling Subsystem

The death of a child increases the emotional vulnerability of surviving siblings. Studies (e.g., Binger et al., 1969) have shown that a significant number of surviving siblings experience changes and problems in coping following the death of a child. These adjustment problems may include poor school performance, the onset of severe enuresis, headaches, school phobia, depression and separation anxieties. Cain et al., 1964 attribute most of the emotional and behavioral problems of surviving siblings to guilt reactions, distorted concepts of illness and death, and comparisons, identification, and misidentification with the deceased sibling.

The impact of illness and death on the sibling subsystem is closely related to the inclusion or exclusion of these children in discussions about the illness and subsequently in the family mourning process. Children who are excluded from understanding the nature of illness and death misinterpret much of what is occurring within the family. The parents preoccupation with the sick child, for example, may be experienced by the sibling as neglect and rejection. The sibling, by over hearing only fragments of information about the illness and how it is being treated may develop a very frightening picture of what is being done to their sibling.

The sibling's ability to receive love and nurturing from the parents may also change dramatically during the course of the illness. The amount of time parents spend with the sick child at the hospital may leave siblings essentially parentless for extended periods of time. This may take on a very literal meaning when children are placed with family relatives or friends for various times during the illness. In other cases the parents are physically present but are too emotionally drained to provide the needed love and attention to the well siblings.

Our review of the impact of child death on the parental, marital, and sibling subsystems in the family is by no means comprehensive. There are numerous other effects that we have not fully explored. The whole family, as a system, can be said to go through stages of grieving similar to those described for individuals in module III. Social and recreational, as well as other aspects of the families lifestyle, are radically altered during the illness and mourning periods. The family faces a seemingly unending list of practical problems, e.g., child care, housekeeping, transportation, etc. The financial costs associated with prolonged illness may dramatically alter the family's lifestyle and effect the style of living for years following the death of the child. The demands for family role reorganization following death which we described in Section C occur also when the deceased family member is a child. While a comprehensive review of the literature on child death is beyond the scope of this module, some of the more significant resources that can assist you in working with dying children and their families are included in the bibliography at the end of the module.

In the next sections, we will begin to look at how the hospice nurse can assess the needs of families and what interventions can be made to sustain the physical and emotional health of surviving family members and prevent the disintegration of the family unit.

## SECTION E. FAMILY ASSESSMENT

We have outlined in earlier sections how the excessive demands upon the family imposed by the chronic illness and death of a member can contribute to the development of multiple health and relationship problems in the family system. We have also tried to develop the reader's appreciation of the existence, multitude, variety, and intensity of changes in the life of the bereaved family. In section E, we will present a model of family assessment that can assist the hospice nurse in formulating a plan of care that encompasses the needs and problems of all family members. The work of Mac Vicar and Archbold (1976), Hill and Hansen (1964) and Rogers and Mengel (1979) were particularly helpful in the development of this model.

The family assessment model we are suggesting is based on nine interrelated, but conceptually distinct, categories of information. These catagories are briefly outlined below:

1. Make-up of the Family System
    a. What persons constitute the nuclear family (household)?

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b. What are the demographic characteristics of the nuclear family, e.g., age and sex of members, educational background, religion, ethnicity, occupations, marital status, etc.?

c. How could each dyadic relationship within the nuclear family be described?

d. Are there cultural or language barriers that will pose obstacles to serving this family?

e. What persons constitute the extended family?

f. How frequently and in what manner do extended family members interact with the nuclear family?

g. Are the extended family members geographically accessible?

h. What persons constitute the social network of the family?

i. How frequently and in what manner do social network members interact with the nuclear family? (Be sure to include the identification of the social network of the children)

j. Given the above, what members of the extended family and social network may need supportive services in addition to the nuclear family?

2. Characteristics of the Family System

a. What particular stage of the family life cycle is this family in? Are there major transitions, e.g., birth of child, child starting school, retirement, etc. being experienced by the family that will add to the overall stress of family members?

b. How would you characterize the degree of enmeshment or disengagement of this family system?

c. What dyads, triangles, and coalitions exist within the family?

d. How would you characterize the marital relationship, the parent-child relationships, and the sibling relationships?

e. Are there family rules that will inhibit family mourning (e.g., don't cry) and the reorganization of the family?

f. Describe the roles played by each family member. What roles of the dying patient will the family have the most difficulty replacing?

g. Who is the "Strong one"? Who is most likely to exhibit symptoms on behalf of the family?

h. Is there a high degree of fusion between any family members and the dying patient?

i. What are the strengths and vulnerabilities of this paritcular family?

j. How would you describe the current physical and emotional health of the family?

3. Family History of Managing Crises

   a. What past crises have the family experienced?

   b. How and by whom were decisions made during these situations?

   c. What persons in the extended family and social network were relied on during these crises?

   d. What style of problem solving was displayed by the family during these crises?

   e. What roles did each family member play during these situations?

4. Values and Beliefs About Death

   a. What experience have the various family members had with death?

   b. What are the family (personal and/or religious) beliefs about dying?

   c. Are there family myths about dying, e.g., death is punishment?

   d. Has death been talked about in the family? Have any members, e.g., children, been excluded from such conversations.

   e. Which family members, if any, have never attended a funeral and burial service?

5. Understanding of and Response to Current Illness

   a. Do all family members know the illness of the patient?

   b. Does each member understand the nature of the illness and the medical procedures that have been performed or that are continuing to be performed?

   c. What signs of anticipatory grief can be observed among family members?

   d. How has the illness altered the historical pattern of relationships in the family?

e. Has the role reorganization of family members begun in response to the illness? If so, what problems are being encountered by members redefining their family roles?

f. What has been the course of the illness and what institutions and persons have worked with the family since the illness was detected?

g. Are family members able to express their feelings to one another?

h. Can the family talk about the illness and the approaching death?

6. Family Resources

a. What emotional supports are available to the family, e.g., relations, friends, clergy, self-help groups, community agencies, etc.

b. Are the financial resources of the family, e.g., insurance, income, etc. adequate to meet the family's current needs? If not, what supplemental financial assistance might the family qualify for?

c. What additional community services could be utilized by the family e.g., day care services, legal services, etc.

d. What roles of the dying patient will be most difficult for the family to take over? Can such roles be partially performed by extended family or social network members?

e. What resources (time, skill, knowledge, willingness) of the family can be expected in providing daily care for the patient?

7. Immediate Family Needs

a. What are the immediate needs of the family that should be addressed prior to developing a more comprehensive plan of care?

b. Is any other family member in crisis?

c. Are there any family problems with transportation, child care, food and shelter, etc. that need immediate attention?

8. Long Range Family Needs

a. Given the information generated from the preceding categories, what are the needs of the family that must be reflected in the plan for care?

b. What problems do you anticipate that this family will encounter during the coming months?

c. What services do you see the family needing that go beyond the resources of your program? Where and how can such services be obtained?

d. Describe the nature and intensity of the follow up services you anticipate this family will need following the patient's death.

9. The Careproviders

a. Which staff can work best with this family given the age; cultural, ethnic, and religious background; family type; and personalities of this particular family?

b. What characteristics of this family might make it difficult for you to work with them?

The above framework for the assessment of families is intended to serve as a tool to assist the nurse in systematically looking at the needs of families in hospice programs. Are there additional categories or areas of concern you would add to this assessment model? If so, list them below.

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

## SECTION F. FAMILY INTERVENTIONS

Death is one of the few major life events for which our culture has not provided role specific behaviors. Most of us have not learned how to die or how to help someone else die. The demand for nursing skills to help families deal with death originates primarily in the lack of social and cultural skills acquired to address dying and death rather than in the inadequacy or psychopathology of the individuals and families served in the hospice program. As such, the nurse spends as much time in teaching families as in counseling families.

The role of the nurse in working with families varies greatly from program to program and is often highly influenced by the total number of persons and resources that make up the interdisciplinary hospice team. In some programs, social workers or other personnel have been hired specifically to address the emotional needs of the families being served. In other programs, it is the nurse that will provide the majority of support services to families. It is our experience that nurses are playing an increasingly greater role in providing services to the families of dying patients. We have, therefore, tried in the final section of Module IV to outline a broad range of family interventions that can be performed by the nurse. We are aware that the role of each nurse will get defined based on the resources of the specific program the skills and interests of the particular nurse, and the unique needs of each family.

The conceptualization of family centered hospice care is based on the premise that the major goals of family intervention are to:

- Increase the psycho-social support available to the dying patient
- Increase the likelihood that unstated emotional agendas (regrets, sorrows, thank-you's, resentments, expressions of affection, good-byes, etc.) can be made explicit between family members
- Decrease the psychological casualty rate of surviving family members
- Decrease the fragmentation and disorganization of the family system that is frequently associated with a death in the family

To present the range of nursing interventions with families, we have outlined specific nursing goals, and interventions that can be utilized to achieve these goals. These goals and interventions are outlined for the time periods: the period preparing the family for the impending death, the time of death, and the period following the death of the family member. The goals and interventions listed are by no means comprehensive, but should provide the reader an understanding of the diversity of potential family interventions.

### PREPARING THE FAMILY FOR IMPENDING DEATH

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
| 1. To establish a relationship with the family of the dying patient. | a. Meet with the whole family whenever possible. |
| | b. Make individual personal contact with each family member, including all children. |
| | c. Demonstrate positive regard for family members, your respect for family privacy, your respect of family values, etc. |
| | d. Communicate your role in the program and the nature of support you can provide the family. |
| | e. Listen to the family! |
| 2. To develop a preliminary family care plan. | a. Conduct an assessment of the short and long range needs of the family, utlizing information received and perceptions of all interdisciplinary team members. |
| | b. Develop a short and long term family care plan based on the assessment data. |
| | c. Assign primary staff responsibility to respond to family concerns. |
| | d. Provide a timely response to the immediate needs of the family. |
| 3. To reduce the family's fear of the unknown | a. Orient the family to the facility, the geographical location of different departments, equipment, and procedures. |
| | b. Clearly explain policies and procedures of the program. |
| | c. All communications with the family should be expressed, repeated, and checked to make sure the family has understood. |
| | d. Provide family members with concise written summary of program policies and procedures |
| | e. Designate one person responsible for orienting each family and who the family may contact as questions arise. |

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
| 4. To involve the family in the physical and emotional care of the patient. | a. Communicate the program's expectations for the family's involvement in the patient's care.<br>b. Teach family members those patient care procedures, e.g., how to turn the patient, dress a pressure area, respond to feeding problems, etc. that can be provided by the family.<br>c. Provide "strokes" to the family for their involvement with the patient and their mastery of patient care techniques.<br>d. Provide nursing back-up, by telephone or visit, to respond to questions of the family on patient care procedures.<br>e. Provide family members on opportunity to talk about day to day problems that arise in caring for the patient and how they feel about providing such care.<br>f. Regularly assess the level of expectations placed on the family for patient care, in light of the family's overall emotional and physical health.<br>g. Encourage the family to involve, where possible, extended family and social network members in the care of the patient to allow "time-out" periods for family members. |
| 5. To maintain the dying patient's participation in the family. | a. Support the family and dying patient to continue normal activities as long as possible.<br>b. Encourage the dying patient's continued participation in family decisionmaking |

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
|  | c. Recognize that emotional distancing between family members and between the family and the patient are common aspects of anticipatory grief Provide members an opportunity to talk about the anticipated loss and reopen communication to whatever degree the family can tolerate. |
| 6. To discourage the development of false hope among family members for the survival of the patient. | a. Explain and prepare the family for the emotional turmoil involved in the remission and relapse process.<br>b. Caution the family on articles in the lay press announcing new medical breakthroughs and miracle cures. |
| 7. To assist the family in dealing with anticipatory grief and other relationship issues in the family. | a. Provide the family opportunities for the expression of feelings, e.g., sadness and sorrow, affection, resentment and anger, etc.<br>b. Confront or intervene very carefully when denial is utilized by families with limited coping abilities.<br>c. Serve as a model for affective communication; some families simply don't have the skills to talk about feelings. You can through your own modeling teach family members the words used to express emotion.<br>d. Involve additional professional resources in cases of extreme pathological grief.<br>e. Try to recognize the scapegoating process as early as possible, and attempt to get the family to discharge the emotion behind each scapegoating--before the scapegoat role is solidified within the family structure. |

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
|  | f. Make explicit facts and feelings that family members experience individually but are afraid to express. |
| 8. To involve the children in the family mourning process. | a. Discuss with adult family members the importance of the children having opportunities to talk about their grief, their fears, their questions, etc.<br>b. Encourage involvement of children in family meetings.<br>c. Clarify unclear and mystifying communication that tends to promote magical thinking in children.<br>d. Encourage and model talking to the children rather than about the children.<br>e. Provide direct communications aimed at relieving the siblings feelings of guilt and responsibility, fears that they will become ill and die, and their fear of doctors and hospitals.<br>f. Communicate about the illness and death in terms commensurate with the developmental level of the child. |
| 9. To reduce the guilt of family members. | a. Provide an opportunity for the family to talk about their "sins of commission and ommission" (regrets) with the dying patient.<br>b. Actively involve the family members in the care of the patient.<br>c. Let family members know that it is often normal to look forward to the time it will all be over or experience some emotional relief at the time of death. |

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
| 10. To support the parenting skills of the parents of a dying child. | a. Recognize and acknowledge the difficult task of being parents of a dying child.<br>b. Support the parents in continuing to set limits for the dying child.<br>c. Recognize and avoid behavior of staff, e.g., possessiveness, that can undermine the adequacy of the parents of the dying child.<br>d. Help the parents balance their time and emotional energy between the dying child and other siblings.<br>e. Help the parents relieve feelings of guilt and blame so they can allow the autonomy of surviving children.<br>f. Discuss with the parents of a deceased child the dangers of creating a replacement child.<br>g. Caution parents on the dangers of overprotecting and overindulging surviving children. |
| 11. To increase the resources available to the family. | a. Based on the initial family assessment and the changing needs of the family, assist the family in obtaining needed resources through extended family and social network members and community agencies. Such needs could include child care, financial aid, homemaker services, transportation, housing, legal services, etc.<br>b. Family member participation in widow to widow programs, self help groups for parents of dying children, and other self help programs should be strongly encouraged. |

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
| 12. To help the family prepare for the practical realities surrounding the death of the patient. | a. Provide information to the family on such matters as the completion of wills, checking the status of life insurance policies, planning funeral and burial arrangements, etc. |
| 13. To reduce the over-extension (physical and emotional exhaustion) of family members. | a. Help the family establish a rotation schedule among relatives and friends to make sure members are getting sufficient physical and emotional replenishment. |
| 14. To support the marital relationship of parents with a dying child. | a. Meet with the parents periodically during the illness to focus specifically on how they are managing individually and as a couple. |

| SUPPORTING THE FAMILY AT THE TIME OF DEATH | |
|---|---|
| NURSING GOALS | NURSING INTERVENTIONS |
| 15. To support the family at the time death occurs. | a. Encourage the family to fully express their grief.<br>b. Assist the family in viewing the patient's body.<br>c. Allow the family to spend as much time with the deceased person as they wish.<br>d. Assist family, if needed, in making funeral and burial arrangements.<br>e. Avoid oversolitiousness and false reassurrances; your physical presence and touch may mean more than your words.<br>f. Again, encourage the family to involve the children in the mourning activities. |

| SUPPORT FOLLOWING THE DEATH | |
|---|---|
| NURSING GOALS | NURSING INTERVENTIONS |
| 16. To assist the family in the resolution of grief and in the restabilization of the family. | a. Maintain regular contact by visit and by phone to allow family members an opportunity to share continuing feelings of grief and loss.<br>b. Invite the family back to the hospice program for regular follow-up groups or for informal visits.<br>c. Assist the family in the reorganization of family roles.<br>d. Help the family plan for the future.<br>e. Identify any family members who may be in need of continuing professional support either through the hospice program or other community agencies. |

Are there other common nursing goals and nursing interventions you would suggest? If so, list them below.

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
| | |

| NURSING GOALS | NURSING INTERVENTIONS |
|---|---|
| | |

## Working with the Patient without a Family

As a concluding note to this module, it is perhaps appropriate to address some brief comments to working with the dying patient who has no family. In reviewing how hospice programs around the country address this particular situation, I have discovered a number of different approaches. The stance of many hospice programs is simply that everyone must be able to face death within a network of family relationships. If the patient doesn't have a family, then part of the role of the hospice program is to create a surrogate family that will support the patient during their final days. In some cases, the patient's friends will become this surrogate family. In other cases, the hospice program seeks to actively involve the patient with a number of community institutions, e.g., churches, to build a supportive network of relationships around the patient. It is also quite obvious that in many cases it is the hospice staff that will become the surrogate family for the patient. Where a patient comes to the hospice without family and friends, it is perhaps the most essential part of hospice care that the patient is "adopted" by the program and key staff play roles with the patient quite similar to those we would expect from family members if they existed. Volunteers within hospice programs may play particularly important roles performing these surrogate family roles with the patient.

It should be recognized that when hospice staff become involved with a patient to the extent that they have taken on surrogate family roles, the death of the patient may have an impact on the hospice staff quite similar to that we have described for the family system. Particular care must be given to allow staff to appropriately grieve the death of the patient for whom the hospice staff had become "family."

## Summary

We have tried in this module to provide a number of concepts and models to increase your understanding of the impact of death on the family system and how you can provide supportive services to families experiencing a death of one of their members. It is our sincere hope that this goal has been met and that the ideas and experiences incorporated into this module will increase your ability to work with dying patients and their families.

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# MODULE V: MANAGING PERSONAL AND ORGANIZATIONAL STRESS IN THE CARE OF THE DYING

PARTICIPANT MANUAL

DEVELOPED BY:
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# MODULE V: MANAGING PERSONAL AND ORGANIZATIONAL STRESS IN THE CARE OF THE DYING

## Purpose and Goals

The purpose of Module V is to assist the hospice care nurse in the development of personal and organizational strategies to reduce the physical and emotional stress experienced in the care of the dying. The goals of the module are to assist participants to:

- Identify personal and organizational factors that contribute to the professional stress of the hospice care nurse
- Develop more effective strategies for stress management in the work environment
- Develop organizational and supervisory strategies to reduce the level of professional stress experienced by those caring for the dying

## Module Content

The Module content includes the following topic areas:

- Operational definitions of professional stress, stressor, stress response, and professional burn-out
- Individual and organizational indicators of professional stress
- The impact of professional stress on family and interpersonal relationships
- The impact of grief (and accumulated grief) and mourning on the hospice care nurse
- Stress management techniques
- Balancing one's personal and professional lives
- Organizational conditions that increase professional stress
- How to structure the work environment to increase role supports and reduce role stressors
- Supervisory responses to reduce professional stress in team members (other nurses, volunteers, etc.)

## Learning Objectives

At the conclusion of Module V, participants will be able to:

- Describe the physiological and psychological symptoms of excessive stress
- Identify their own personal style of stress management and identify their own early warning signs of professional stress
- Describe at least three stress management techniques
- List at least three unique aspects of professional stress in the field of hospice care
- Diagram their own replenishment and support network
- Discuss three levels of incestuous organizational closure that can significantly increase the level of stress experienced by hospice care workers
- Identify and define at least three role conditions that produce excessive stress in the hospice care nurse
- List and describe at least eight organizational strategies to reduce role stressors and increase role supports for the hospice care nurse
- Describe effective supervisory responses to professional stress experienced by other members of the interdisciplinary team

Module V has been divided into three major content areas. In Section A, we will look at the nature of professional stress experienced by the hospice care nurse, its etiology and debilitating effects. Particular attention will be focused on the stress inherent in the relationship between the nurse and the dying patient. Section B will focus on the organizational context of professional stress. We will examine those organizational processes and role conditions that exacerbate the level of stress within the hospice program. Suggestions will be offered on how mechanisms of stress reduction and staff support can be built into the hospice care program. Section C will conclude the module with a focus on effective supervisory responses to professional stress experienced by other members of the interdisciplinary team. Individual and group exercises have been integrated into the module to give you an opportunity for personal introspection and an opportunity to share your ideas and concerns.

## A. PERSONAL STRATEGIES TO MANAGE PROFESSIONAL STRESS

We will first define some key terms and look at some models for understanding the nature and impact of stress. Theorists from fields as diverse as internal medicine to cultural anthropology have tried to define and describe the nature of stress, often disagreeing vehemently over the precise wording of key definitions and theoretical constructs. To avoid confusion over the use of certain words and phrases, the following definitions of stress, stressor, stress response, professional stress and professional burn-out are presented and briefly discussed.

These definitions will give us a common vocabulary and a common set of understandings that we can utilize throughout the module.

STRESS IS THE DEMAND UPON THE HUMAN BODY FOR AN ADAPTATIONAL CHANGE

Such demands occur constantly and concern us primarily when the level of stress exceeds our capacity to effectively respond. Stress and our body's continual response represent the delicate and intricate mechanisms through which we maintain balance with our social and physical environment. To be free of stress is to cease living. When we say someone is under a lot of stress, we usually mean excessive and unpleasant stress, or distress. When we speak of stress in this module, we will mean excessive and unpleasant stress.

STRESSORS ARE THOSE SITUATIONS, CONDITIONS, OR AGENTS THAT PRODUCE STRESS.

We will be focusing primarily on psychosocial stressors--those stressors that emerge in the relationship between the hospice nurse and the dying patient and the patient's family, and those stressors that arise within the emotional climate of the hospice care program. In Section B of this module, we will talk about role stressors that relate to the unique definitions and constraints of our roles within a particular program. A stressor is simply a stimulus that causes stress. What are some examples of stressors you have experienced in the last 24 hours?

1. ______________________ 2. ______________________

3. ______________________ 4. ______________________

THE STRESS RESPONSE IS THE GENERALIZED AND SPECIALIZED REACTIONS OR ADAPTATIONS OF AN INDIVIDUAL TO STRESS.

We refer to the stress response as generalized due to the work of Hans

Selye (1974, 1976) who pioneered the concept of the General Adaptation Syndrome (G.A.S.). The G.A.S. represents a stereotyped response of the body to stress irregardless of the particular stressor. This generalized response occurs in three phases: 1. the alarm reaction, 2. the stage of resistance, and 3. the stage of exhaustion, each with its own concomittant physiological changes and hormonal activity. In addition to the generalized nature of the G.A.S., each individual responds in their own unique manner to prolonged and excessive stress. This specialized adaptation to stress represents our own unique style of stress management. Later in the module we will try to identify your unique style and examine ways in which it can be improved.

PROFESSIONAL STRESS IS THE DEMAND FOR ADAPTATIONAL CHANGE EXPERIENCED IN THE PERFORMANCE OF ONE'S PROFESSIONAL ROLE.

Professional stress tends to center on demands that threaten our self esteem and prevent our effective role performance in the organization.

PROFESSIONAL BURN-OUT IS A DETERIORATION IN ONE'S PERSONAL AND INTERPERSONAL PERFORMANCE THAT IS DIRECTLY RELATED TO CONTINUED CONTACT WITH HIGH STRESS WORK ENVIRONMENTS.

The term "professional burn-out" has come into common useage during the last few years to describe the stress related deterioration in performance of health professionals. Later, in Exhibit V-A, we will look at some of the signs and symptoms of this burn-out process.

## UNIQUE ASPECTS OF PROFESSIONAL STRESS IN HOSPICE CARE

Each setting in which the nurse practices has stressors that tend to be unique for that setting. These stressors have been described for the intensive care unit (Hay, Oken, 1972; Vreeland, Ellis, 1969), the coronary care unit (Cassem, Hackett, 1972; Layman, 1972), the medical oncology unit (Parker et al, 1978; Newlin, and Wellisch, 1978; Goodell, 1980), and the palliative care unit (Blszterczey, 1977).

Some of the unique aspects of professional stress experienced by the nurse in hospice care include the following:

- The nature of the patient. Continued work with dying patients and their families stirs primitive emotions of attachment and loss in the hospice nurse. The problems of anticipatory grief, grief and mourning, and accumulated grief for the hospice nurse are more intense in this setting than in any setting in which the nurse practices.

- The nature of successful care. The nurse has been trained to evaluate success as cure--the restoration of the health and functioning of the patient. Successful care has dictated the saving of human life. In hospice care nurses are confronted with the impotence of medical technology to save the lives of their patients and are confronted with forging new criteria for successful care. As the nurse struggles to maintain or create dignity and meaning in the life of the dying patient, there is a tendency to compensate for technical impotence to save the patient's life by personally overextending oneself to serve the dying patient. In short, the hospice care nurse is by definition in a very emotionally vulnerable role.

- The redefinition of service roles. The hospice nurse must redefine and broaden the traditional role for which she or he has been trained. There are demands for knowledge and skills which were only cursorily reviewed in the nurse's formal training, e.g., knowledge of death and dying, communication skills, individual and family counseling skills, etc. Such skill and knowledge demands represent a primary source of stress for the hospice care nurse, particularly early in their experiences caring for the dying patient and family.

- The hospice nurse may find greater responsibility in decision making within the hospice program than was experienced working in other settings.

- The continuing controversy over hospice care both in the professional and lay communities forces hospice nurses to feel as if they are working in a fish bowl.

- The financial instability of many hospice programs will continue as a stressor for service providers until more stable sources of funding for hospice care are developed.

- Those hospice care nurses working in home care may be particularly vulnerable due to the stress of their isolation and the constant adjustment to the various home settings.

- The internal politics and personalities within the hospice field may inadvertently contribute to the stress of the hospice care nurse. Like any emerging health care field or social movement, the hospice field must proceed through various ideological battles as the field struggles to define itself. The primitive emotional climate created by such battles may be experienced as a source of personal stress and an unnecessary nuisance to the nurse concerned primarily with patient care.

- Which of the above do you see as most important?

  ______________________________________________________________

- What other stressors do you see as unique to the field of hospice care?

  ______________________________________________________________

  ______________________________________________________________

  ______________________________________________________________

  ______________________________________________________________

  ______________________________________________________________

  ______________________________________________________________

## THE PHYSICAL AND PSYCHOLOGICAL INDICATORS OF PROFESSIONAL STRESS

Our concern with professional stress in the hospice care nurse is based on our concern for the physical and emotional health of the individual nurse and the destructive impact of excessive stress on the quality of care for the dying. Exhibit V-A on the following page categorizes some of the physical and psychological indicators of professional stress that may be experienced by the hospice care nurse. A review of this chart reveals the far reaching and deteriorating influence of professional stress upon our physical health, self-esteem, and interpersonal relationships.

## FACTORS DETERMINING OUR RESPONSE TO PROFESSIONAL STRESS

A number of researchers have developed models to help us understand and predict our responses to stress in the work environment. McLean (1979), has outlined a model which has been modified for use in this module. McLean's model looks at three elements to determine whether a particular stressor will produce a dysfunctional stress response. These elements include individual vulnerability, the organizational and social context in which the stressor occurs, and the intensity and duration of the particular stressor. The interaction of these three factors in determining the stress response of the hospice care nurse is graphically portrayed in Exhibit V-B.

It is important to understand each of these three areas if we are to develop personal and organizational strategies to enable the hospice care nurse in the effective management of professional stress. Each area will be discussed below.

## INDIVIDUAL VULNERABILITY TO PROFESSIONAL STRESS

Each hospice care nurse possesses a unique vulnerability to stress in

# EXHIBIT V-A

# INDICATORS OF PROFESSIONAL STRESS

| Health Indicators | Excessive Behavior Indicators | Emotional Adjustment Indicators | Relationship Indicators | Attitude Indicators |
|---|---|---|---|---|
| Fatigue and chronic exhaustion<br>Frequent and prolonged colds<br>Headaches<br>Sleep disturbances--insomnia, nightmares, excessive sleeping (escape)<br>Ulcers<br>Gastro-intestinal disorders<br>Sudden losses or gains in weight<br>Flare-ups of pre-existing medical disorders, e.g., diabetes, high blood pressure, asthma.<br>Injuries from high risk behavior<br>Muscular pain, particularly in lower back and neck<br>Increased premenstrual tension<br>Missed menstrual cycles<br>Excessive sweating and urination<br>Bruxism (grinding of the teeth) | Increased consumption of caffeine, tobacco, alcohol, over-the-counter medications, psychoactive prescription drugs, illicit drugs<br>High risk taking behavior--auto/cycle accidents, falls, "high risk" hobbies, general proness to accidents and injuries, gambling<br>Extreme mood and behavioral changes<br>Increased rpopensity for violent and aggressive behavior<br>Over and under eating<br>Hyperactivity | Emotional distancing<br>Paranoia<br>Depression-loss of meaning, loss of hope<br>Decreased emotional control<br>Martyrdom<br>Fear of "going crazy"<br>Increased amount of time daydreaming/ fantasy<br>Constant feelings of being "trapped"<br>Nervous ticks<br>Undefined fears<br>Inability to concentrate<br>Guilt for being healthy<br>Intellectualization<br>Preoccupation with one's own death<br>Overidentification (delusional belief that one is dying)<br>Inappropriate guilt over death or injury of patient<br>Visualization of what is occurring inside patient's body | Isolation from or overbonding with other<br>Responding to patients in mechanical manner (Focus on disease - not on death)<br>Increased isolation from patients<br>Increased anger at patients<br>Increased interpersonal conflicts with other staff<br>Increased problems in marital and other interpersonal relationships away from work, including relationships with one's children<br>Social isolation | Grandiosity<br>Boredom<br>Cycnacism<br>Sick humor--aimed particularly at the patient<br>Air of righteousness<br>Hyper-critical of program and/or peers<br>Expressions of hopelessness and frustration<br>**Value Indicators**<br>Loss of faith<br>Spiritual crisis<br>Sudden and extreme changes in one's values and beliefs |

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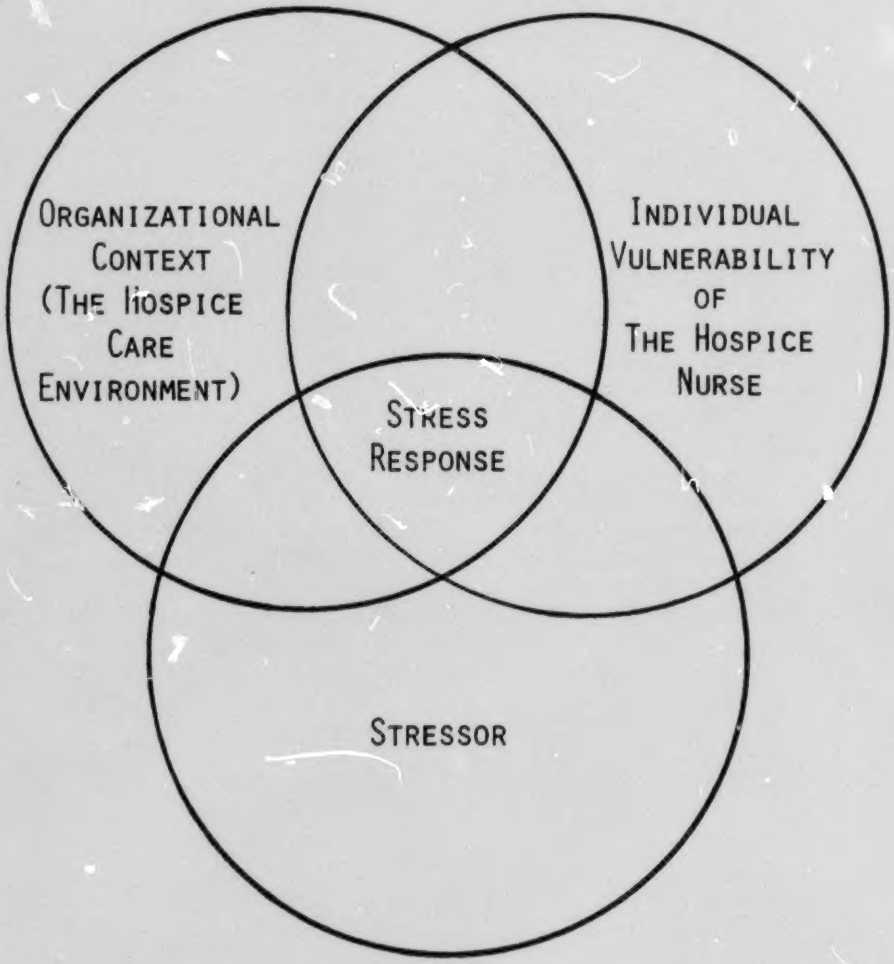
## EXHIBIT V-B: FACTORS AFFECTING INDIVIDUAL STRESS RESPONSES*


ORGANIZATIONAL CONTEXT (THE HOSPICE CARE ENVIRONMENT)
INDIVIDUAL VULNERABILITY OF THE HOSPICE NURSE
STRESS RESPONSE
STRESSOR

*ADAPTED FROM McLEAN, 1979

the provision of care for the dying patient and their family. Some of the factors that influence this vulnerability are illustrated in Exhibit V-C.

Each nurse brings a unique genetic and developmental history that influences the capability to withstand stress.

Our prior history of stress management is perhaps one of the best predictors of how well we can sustain ourselves in the high stress environment of the hospice care program. These stress management histories reflect enduring aspects of our personalities and the evolutionary changes that occur in our stress response pattern during the sequential stages of our lives. Do we tend to internalize or externalize stress? Are we able to verbalize deep emotions? Can we seek emotional support when we need it?

Our professional training greatly influences our vulnerability to stress in the work environment. Did our professional training prepare us with the knowledge and skills to effectively provide hospice care? Authors such as Roach (1978), Vachon (1978), and Quint (1964) have poignantly and articulately described the need for the more adequate preparation of the nurse to minister to the needs of the dying.

One's values and beliefs play a particularly important role in the vulnerability of the hospice care nurse. The constant confrontation with death requires a set of personal, philosophical, or spiritual values that allows one to come to grips with the meaning of death--and life.

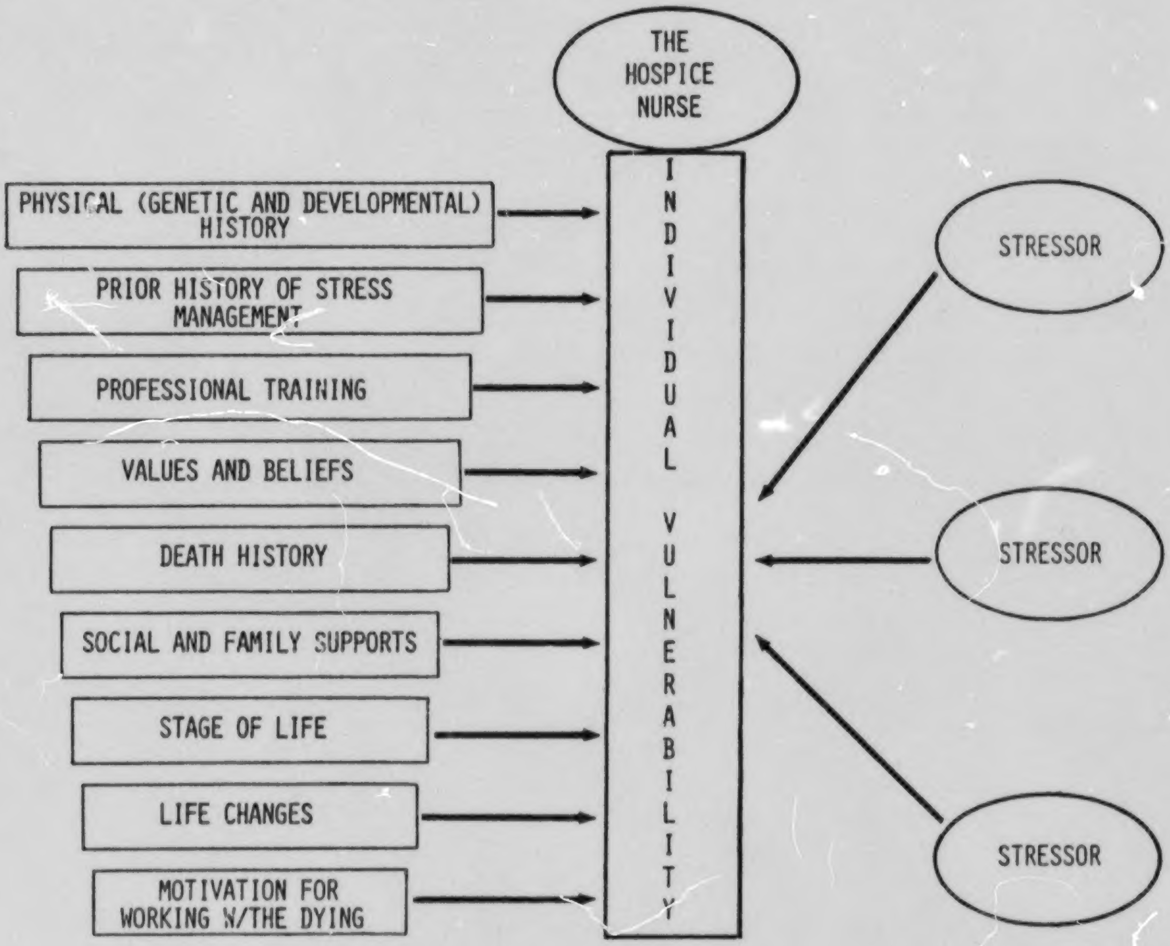
Each nurse brings to the hospice program a unique death history--a composite of values, emotions and experiences regarding death. One's own unresolved issues regarding personal losses of family or intimate friends inevitably arise in providing care to the dying and increase one's emotional vulnerability.

The existence of a family and social support network through which we can seek emotional replenishment greatly decreases our vulnerability to professional stress.

Our vulnerability to stress changes through various developmental periods of our life just as our methods of coping change over time. Many persons, for example, experience a "mid-life crisis" marked by periods of emotional distress and changes in personal values and commitments. Such personal developmental crises increase our vulnerability to professional stress.

Both the intensity and number of life changes that one experiences in a short period of time influence our capacity to withstand stress in the work setting. Rapid and dramatic changes in our personal life may quickly deplete the emotional resources needed to provide hospice care. Holmes and Rahe (1967) have developed a scale to measure recent life changes--what they refer to as life change units (e.g., deaths, divorce, illness, pregnancy, change in occupation, etc.). Their research revealed a significant connection between the onset and severity of illness and increases in life change units. For our purposes, we can merely say that one's vulnerability to pro-

EXHIBIT V-C: FACTORS AFFECTING INDIVIDUAL VULNERABILITY OF THE HOSPICE NURSE


THE HOSPICE NURSE
PHYSICAL (GENETIC AND DEVELOPMENTAL) HISTORY
PRIOR HISTORY OF STRESS MANAGEMENT
PROFESSIONAL TRAINING
VALUES AND BELIEFS
DEATH HISTORY
SOCIAL AND FAMILY SUPPORTS
STAGE OF LIFE
LIFE CHANGES
MOTIVATION FOR WORKING W/THE DYING
INDIVIDUAL VULNERABILITY
STRESSOR
STRESSOR
STRESSOR

fessional stress increases with the number of life change units we experience in a relatively short period of time.

Vachon (1978) has provided an insightful analysis of how one's motivation for working with the dying influences vulnerability to professional stress. Her typology is briefly summarized in Exhibit V-D. Vachon does not feel the motivations listed are the only motives for working with the dying, but do represent particular motives that can influence how we experience stress in providing hospice care.

## ORGANIZATIONAL CONTEXT

In addition to individual vulnerability, the organizational context strongly influences the stress response of the hospice care nurse. This organizational contect of professional stress will be discussed in detail in Section B of his module. For now, it is merely important to recognize that organizational factors operate to increase or decrease the vulnerability of the hospice care nurse. Such factors include:

- The stability of the organizational structure
- The emotional climate of the organization
- The organizational culture and values
- The accessibility of outside resources
- The nature of professional peer relationships
- The nature of supervisory supports
- The availability of mechanisms to resolve interpersonal conflicts
- The adequacy and comfort of the physical environment

## STRESSORS

The third component of our model to understand the stress response of the hospice care nurse is the stressors. Stressors--those situations causing stress--may originate from conditions or relationships within the hospice care program.

Two of the major sources of stress will be briefly discussed--the "reality shock" experienced by nurses moving from traditional hospital settings to the hospice environment and the stress produced by the repetitive losses via death experienced by the hospice care nurse.

Kramer (1974), and Schmalenberg and Kramer (1976) have eloquently described the "reality shock" experienced in the transition from the nursing school subculture to the new and unfamiliar work subculture of nursing practice. Each of these subcultures has a set of distinct values and role specific behaviors that the nursing student and the practicing nurse must perform. The vast discrepancy between the two subcultures is a source of intense stress as the person moves from the educational to the work setting.

The notion of "reality shock" can also be applied to the transition of

## EXHIBIT V-D

## MOTIVATIONAL FACTORS INFLUENCING ONE'S STRESS RESPONSE IN THE CARE OF THE DYING*

| MOTIVATION FOR WORKING WITH THE DYING | STRESS RESPONSE |
|---|---|
| 1. Accidental or out of convenience | Emotional involvement with patients minimized; stress experienced from lack of knowledge and feelings of professional impotence; As emotional involvement increases, so do emotional risks. |
| 2. "in-thing"/wish to affiliate with charismatic leader | Stress increases dramatically as one discovers dying patients are not "all young, beautiful, and articulate people who are longing to spend their dying months talking about their philosophy of life and death" (Vachon, 1978) and as the human chinks appear in the armour of the charismatic leader. |
| 3. Intellectual appeal | This scientific approach may break down as person becomes emotionally involved with patients. As intellectualization breaks down, the person is highly vulnerable. |
| 4. Sense of "calling" | The missionary zeal may result in overcommittment and over-involvement with patients. The person is very prone to physical and emotional exhaustion. |
| 5. Past personal experience with death | Previous unresolved grief may result in overidentification with dying patients. Person's overinvolvement with patients produces emotional depletion and conflicts with other staff. |
| 6. Suspicion that one will develop the disease | Overidentification with the patient. Highly vulnerable when a number of patients die in short period of time. |

*Adapted from M.L.S. Vachon's "Motivation and Stress Experienced by Staff Working With the Terminally Ill" (Vachon, 1978) the nurse from traditional medical settings to the hospice. In traditional medical settings everything is geared to fighting death with the best of medical technology; in the hospice program the focus is on assisting the patient to accept death with as much comfort and dignity as is possible. In the hospital subculture nurses are taught to minimize the emotional responses of the patient and family through the use of sedatives and tranquilizers, enforcement of visiting hours, focus on physical care, and referral of emotional issues to social workers, psychiatrists and clergy (Benoliel, 1974). In the hospice subculture, a primary role of the nurse is responding to the emotional and other nonphysical needs of the patient and the family. In the hospital subculture special emphasis is placed on the nurses emotional control and composure. In the hospice subculture much greater emphasis is placed on emotional self disclosure and the nurses "use of self" in the caring process. The list could go on, but the critical point is that there are significant stressors placed upon the nurse as she or he moves into the field of hospice care. Such stressors require special support systems to assist the nurse in assimilating the values and role specific behaviors appropriate to hospice care. Some specific support systems that can assist in this transition will be discussed in Section B.

The most primitive and continuing stressor for hospice care nurses is the anticipatory grief and grieving of the death of patients with whom they have become so intimately involved. These deaths are experienced differently by individual nurses and the intensity of the grieving response differs from patient to patient. There are some deaths, particularly of children, that all staff grieve deeply. Others may be experienced less intensely, particularly when the person has suffered a prolonged and unusually painful illness. There is an undefined chemistry that enables us to form powerful attachments to some patients and minimal attachments to others. We may feel strong alliances with a particular patient because they are our same sex, age, background, etc. or because they rekindle associations with others we have loved. The ability to manage an almost constant grief and mourning process is perhaps the most critical factor in determining whether the hospice care nurse can emotionally survive in the professional care of the dying.

Nurses utilize a number of defenses to allay the anxiety produced from their relationships with dying patients and their families. Quint (1965, 1966) catalogued a number of such defenses that tended to decrease interaction with and create emotional distance between the nurse and the dying patient. Benoliel (1974) first identified this social and emotional distancing from dying patients as part of a generalized syndrome of anticipatory grief. If we assume that there are sequential stages of grief and mourning that must occur before one reaches some level of personal resolution to death and that the experience of these stages may severely influence an individual's emotional health; then we must look carefully at the hospice care nurse who may experience a number of these stages of grief and mourning simultaneously as a result of experiencing the death of several patients in a short period of time.

These losses are particularly acute in the hospice environment. The hospice philosophy with its emphasis on intense interpersonal care, active involvement of the patient's family, and openess to the emotional and spiritual needs of the patient creates more fully developed relationships than could exist in traditional medical settings. It should not be surprising that, in the absence of substantial personal and professional supports, the hospice nurse could be overwhelmed by the confrontation with death, depression, and hopelessness and seek some degree of emotional distance between themselves and their patients. Vachon (1978) has noted that some nurses may act out (e.g., sexual acting out, excessive drinking, risk taking) as an affirmation of life when overwhelmed with this confrontation with death.

Harper (1977) has developed a model that describes the developmental and coping sequence that occurs in persons working with dying patients. She contends that persons evolve through the following five stages:

INTELLECTUALIZATION

During this initial confrontation with death and dying, the caregiver focuses on the disease processes rather than upon death. The involvement is primarily intellectual and philosophical rather than emotional or personal. Death is unacceptable.

EMOTIONAL SURVIVAL

The caregiver's intellectual defenses break down and they emotionally experience the trauma of death. The caregiver is overwhelmed with personal feelings--guilt for being healthy, repulsed by physical disfigurement, and intense fear of contracting, or believing one has the disease. The caregiver dreams of the dying patients, and one's own past issues of death are brought to the surface.

DEPRESSION

The caregiver becomes depressed and emotionally exhausted. They often are fully experiencing death, grief, and mourning for the first time. It is during this stage that the caregiver accepts the reality of death and the dying process or chooses to leave the field.

EMOTIONAL ARRIVAL

The caregiver becomes free from overidentification and overinvolvement with patients and emerges from the depression. The caregiver continues to experience emotional pain, but is free from its debilitating effects.

DEEP COMPASSION

In this final stage, the caregiver responds to patients compassionately in full acceptance of their impending death. The caregiver has achieved a great deal of self-awareness about the dying process and their potential role with the dying patient. The caregiver is much more comfortable with patients and increasingly communicates with physical as well as verbal contact. The caregiver has matured professionally, developed their own personal values, and realistically accepted illness and death.

Do you feel Harper's model adequately describes the stages you have experienced working with the dying patients? Which stage most clearly describes your current response to death in the hospice setting?________________

To identify how your response to death has changed over time, complete the following two exercises and then compare your answers.

Try to remember the first death of a patient you experienced as a nurse. Reflect for a few minutes on your relationship with this person and your emotional responses to their death. Describe your response.

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

Remember the most recent death of a patient you have experienced as a nurse. Reflect for a few minutes on your relationship with this person and your emotional response to their death. Describe your response.

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

In examining the nurse's experience with death in the hospice care environment, it is important to distinguish between the nurse's response to the dying process and the response to the death event. We may, for example, overemphasize the stress/grief experienced in the death of a patient while neglecting the stress experienced by the nurse in the process that preceeded death. The nurse may experience more stress due to the inability to adequately meet the needs of the patient and the family than from the actual death of the patient. Patients who die before the hospice has had significant involvement with the patient and the family, and patients who suffer for inordinately long periods before their death may provoke excessive levels of stress for the hospice care nurse.

There are other stressors frequently experienced by the hospice nurse. The lack of resources is one such stressor. In some areas, the home care nurse may not have the backup of adequate inpatient services. In other areas, the inpatient nurse may be confronted with the lack of available home care services for discharged patients. The need to say no to patients requesting hospice care, due to restrictive admission criteria or because of the small capacity of the hospice program, may prove particularly troublesome to the nurse coordinator. This is particularly true when local publicity has created an increased demand for hospice care services. The hospice nurse is also frequently caught in the family's conflicting feelings about the impending death of the patient. The family's anger at the patient may be projected onto the caregivers, the family may split members of the team into "good nurse"/"bad nurse", etc. All of these situations can contribute to the stress experienced by nurses in the hospice program.

It is very clear that mechanisms of staff support must be built into a program to emotionally sustain the nurse's daily response to illness and death. It is not surprising that the team approach is such an integral part of hospice care. A staff person from one hospice clearly stated the point by noting that "Living in a community whose business is the care of the very ill and of the dying is so hard that perhaps only a community can sustain it." (West, 1974).

To summarize, we have looked at three factors that determine the stress response of the hospice nurse: INDIVIDUAL VULNERABILITY, ORGANIZATIONAL CONTEXT, AND SPECIFIC STRESSORS. We will conclude Section A by reviewing personal strategies for effectively managing professional stress. Section B will review organizational strategies to assist the hospice nurse in managing professional stress.

## PERSONAL STRATEGIES FOR MANAGING PROFESSIONAL STRESS (OR, HOW TO GET SUPPORT WHILE YOU'RE GIVING IT)

In the following discussion, twelve general approaches to decreasing one's vulnerability to the debilitating effects of professional stress will be outlined and twelve specific stress management techniques will be catalogued.

The general approaches outlined below represent strategies that have proven to ameliorate the effects of excessive stress. There are, however, significant obstacles in their application. The socialization of the nurse to continually respond to the needs of others while denying his or her own needs is one of the major barriers. The socialization of the nurse to deny feelings of guilt, fear, anger, frustration, helplessness and hopelessness--to function as a competent technician bereft of human needs--presents the major obstacle for the nurse in managing professional stress. It is a cruel side effect of such conditioning that to sacrifice is the norm and to take care of one's own needs the exception. Managing professional stress is predicated upon our recognition of the perceived legitimacy of, and our responsiveness to our own needs. It is further predicated on the notion that we cannot effectively respond to the needs of others when our own unmet needs leave us physically and emotionally exhausted. In short, we have to get, to give.

1) The cardinal rule in stress management is KNOW THYSELF! It is only when we begin to understand our needs, our vulnerabilities, and our emotional limits that we can begin to anticipate and counteract professional stress.

| What stressors are most troublesome in your current role? | When you experience these stressors how do you respond? |
|---|---|
| 1. ______________________ | 1. ______________________ |
| 2. ______________________ | 2. ______________________ |
| 3. ______________________ | 3. ______________________ |
| 4. ______________________ | 4. ______________________ |

How would you describe your current style of professional stress management?

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

______________________________________________________________

Ask two of your co-workers to describe how they see you responding to professional stress. How do their answers compare with the description you gave above?

Pace Setting. We each have a unique pace at which we can optimally operate within the work setting. Maintaining a pace consistant with our biological nature reduces the physical wear and tear of stress. We must recognize whether we are a turtle or a racehorse and act accordingly.

While each has value, to ask the turtle to model the racehorse (and vice versa) would be patently absurd.

Limit Setting. Recognize the limits of your knowledge and expertise. Learn to say "I don't know." Recognize the limits of your physical energy and how these limits change. Learn to say "No, I can't" to additional role responsibilities during periods of low physical energy. Recognize the limits of those situations you cannot emotionally handle alone. Learn to say "I need help." Recognize the limits of your emotional endurance. Learn to say "I need time for myself." Clarify the priorities between your responsibilities to work and your responsibilities to those you love outside of work. Decide under what conditions you must clearly say "Their needs come first."

2) Listen to Your Early Warning Signs. It is very important that we each learn to identify our own unique early warning signs of excessive stress. These symptoms represent an internal feedback system that tell us when we are reaching the limits of our physical and emotional defenses. To ignore such symptoms is to invite serious physical and emotional illness.

These symptoms may also indicate:

- Areas of needed skill development
- A need for time out periods (vacations, etc.)
- Our need to take the next step in our professional development, e.g., school, job change, etc., (in response to feelings of boredom, being trapped).
- Personal needs outside the work setting which are being neglected
- The need to re-establish a more equitable balance between our work life and our personal life.

Review the chart of indicators of professional stress displayed earlier in the module (Exhibit V-A). Check which of the following categories you are most susceptible to and then list your specific early warning signs.

☑

☐ Health Indicators

1.

2.

3.

☐ Emotional Adjustment Indicators

1.

2.

3.

☐ Relationship Indicators

1.

2.

3.

☐ Excessive Behavior Indicators

1.

2.

3.

☐ Attitude Indicators

1.

2.

3.

☐ Value Indicators

1.

2.

3.

Other

1.

2.

3.

Ask at least two of your co-workers what signs indicate to them that you are experiencing excessive stress? List their observations.

3) Express Thyself. The mutual expression of human emotion between the hospice nurse and the dying patient and their family represents the very essence of hospice care. The ability to express such emotion is also critical to the emotional survival of the hospice nurse. The primitive emotions which surface in work with the dying must have an outlet. The pain and rage absorbed from the dying patient and their family must be released. The resolution of the anticipatory grief, grief and mourning and accumulated grief experienced by the hospice nurse all hinge on emotional expression. The expression of affection and concern must also occur.

Identify when, where, and with whom you can safely ventilate feelings elicited from your work experiences. Utilize co-workers and persons outside your specific program. Expressing deep emotion, like other areas of communication becomes easier with practice. Take the risks of sharing. If this is a particularly difficult area for you, you may want to seek out some specialized training in affective communication skills.

4) Seek Physical Replenishment. Exercise, nutrition, sleep and sexual nuturing all play an important role in decreasing the debilitating effects of professional stress. Another often neglected area is our need for physical stroking and physical comforting. While we emphasize physical touch in the care of the dying, we frequently ignore the needs of the caregiver for such contact.

5) Seek Social and Emotional Replenishment. Each hospice care nurse must have a support network from which they can draw emotional sustenance. This network should include both persons from the profession and persons who have no affiliation with one's work. Numerous studies have shown that the most debilitating effects of stress can be sharply reduced through social support. Actively develop and use your support network. Your long range effectiveness and contribution to the care of the dying may depend more on your ability to emotionally replenish and nurture yourself outside of the work setting than on the knowledge and skills you bring to the hospice field.

6) Seek Intellectual Replenishment. Identify those knowledge and skill deficiencies that often produce stress for you in the work setting. Develop a continuing education and training plan to overcome these deficiencies. Seek educational opportunities that keep you abreast of broader developments in the field of nursing and in other areas of interest. Find and cultivate mentors who can provide role models and a source of intellectual and personal support.

7) Seek Spiritual Replenishment. Work with the dying inevitably provokes one to seriously reflect on the value and meaning of one's own life. Many hospice nurses have experienced a "crisis in faith" in which they questioned their personal and religious values and beliefs. In an HCS, Inc. survey of hospice nurses, a large number of the nurses indicated that their personal and religious beliefs provided an important resource for managing stress in the care of the dying. While these belief systems differ widely from nurse to nurse, the existence of such a belief system provides an important source of personal strength for the hospice nurse. As graphically displayed in Exhibit V-E, the caregiver must develop a system of values and beliefs that first reconciles them to the realities of death and dying and from that experience secondly provides a personal framework for the value and meaning of life. This belief system can buffer the nurse from many of the worst consequences of professional stress. Cultivate opportunities to explore with others your personal values and beliefs about the meaning of life and death.

8) Develop Boundaries Between Your Personal and Professional Lives. Work with the dying can be emotionally consuming and have unexpected repercussions on one's personal and family life. While it is important that spouses and children understand the nature of our work (and why of necessity we must sometimes receive calls in the middle of the night), the home should be a shelter from, not a continuation of, the intensity of the work environment. It is crucial that we have a professional support group so that our spouses, families, and friends are not continually confronted with our problems at work.

Constantly regulate the balance between your work life and your personal life so that more and more of your time and energy is not consumed by work.

Avoid developing a work-oriented social network. When our social relationships away from work are merely a continuation of our professional relationships in the work setting, our whole life can begin to seem like a constant confrontation with pain and death.

Develop decompression routines. A decompression routine is a ritual that signals to ourselves and others that one part of our life is ending and another part is beginning. These routines represent a "rite of passage" from our work life to our personal life. These rituals, e.g., jogging, a hot bath, reading the newspaper, etc. allow us to diffuse the emotional energy from work and enter our personal lives in a more relaxed manner. What decompression routines do you now use regularly?

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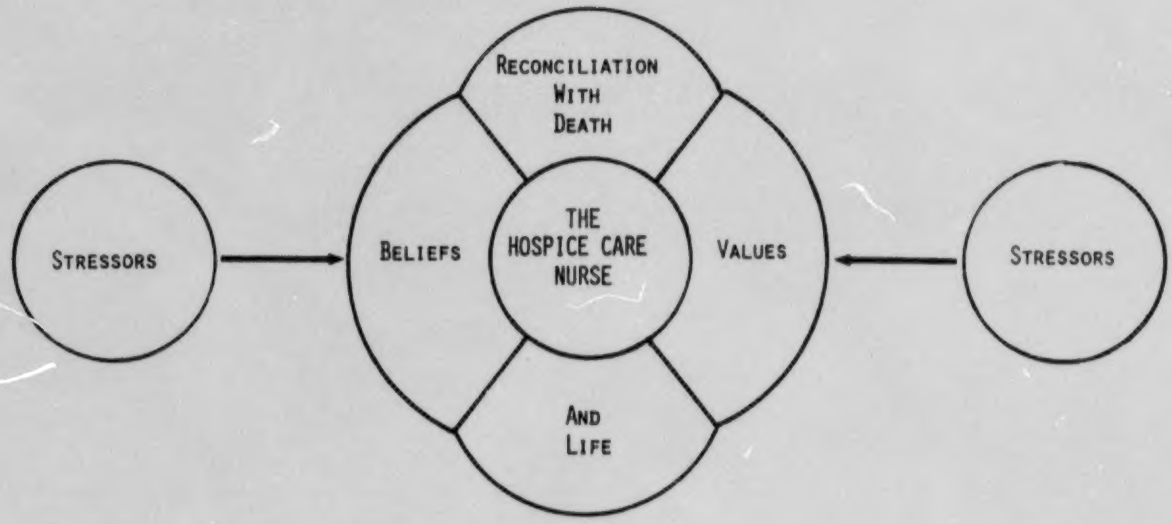
## EXHIBIT V-E: STRESS AND THE BELIEF SYSTEM OF THE HOSPICE CARE NURSE


Reconciliation
With
Death
Stressors
Beliefs
The
Hospice Care
Nurse
Values
Stressors
And
Life

9) Avoid the Superperson Syndrome. The hospice nurse may set unrealistic expectations upon themselves as they provide nurturing, taking care of, organizing, and parenting kinds of activities at work only to return home to provide more nurturing, taking care of, organizing, and parenting kinds of activities--never able to accomplish all that needs to be done. Decide what can and cannot be realistically accomplished and then negotiate, or fight for, as the case may be, a reasonable and equitable division of labor among family members.

10) Develop Alone Time Activities. Don't neglect the nurturing aspects of private time by yourself. Set aside time for your own introspection and reflection. Develop and regularly use activities, e.g., hobbies and pastimes that give you personal pleasure and allow you to escape from all your role responsibilities, e.g., nurse, spouse, parent, friend, etc.

11) Utilize time-out periods. Take regular breaks during each day to replenish yourself--sit and relax, go for a walk, etc. Utilize vacation, mental health days, and compensatory time to physically and emotionally nurture yourself.

12) Relax and have a good time. Given the solemn nature of the work of the hospice nurse, it is very easy to see how one could neglect our need to play, to celebrate life, and to celebrate our affection for one another. A great deal of our professional stress may reflect our own need to take ourselves too seriously and our own intense and rigid approach to life. We must each struggle to attain our highest aims, but we must avoid becoming sacrificial victims to the debilitating effects of stress in the process.

We could summarize these approaches to professional stress by simply stating that if we are to respond to the needs of the dying, we must experience the richness of living.

When we review these twelve approaches to managing professional stress, it is clear that we each must have a replenishment network to offset the emotional intensity of caring for the dying. To assess the adequacy of your current support system, complete the replenishment network diagram as per the directions of the instructor. In which support areas are you most deficient?

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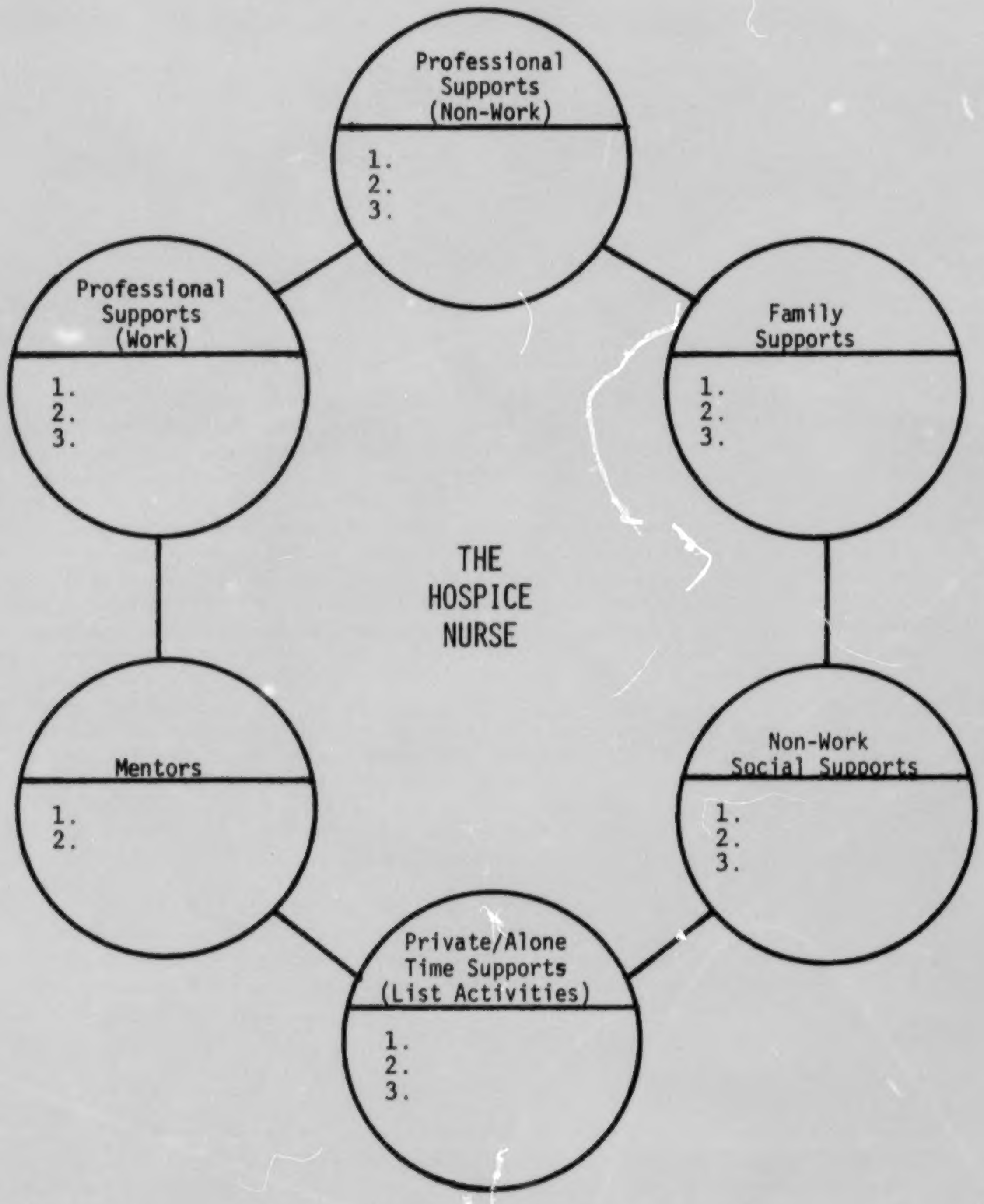
# EXHIBIT V-F: REPLENISHMENT NETWORK DIAGRAM


Professional Supports (Non-Work)
1.
2.
3.
Family Supports
1.
2.
3.
Non-Work Social Supports
1.
2.
3.
Private/Alone Time Supports (List Activities)
1.
2.
3.
Mentors
1.
2.
Professional Supports (Work)
1.
2.
3.
THE HOSPICE NURSE

ⓒ 1980 William L. White, used with permission.

Review the twelve general approaches to managing professional stress. What other strategies have you found helpful in managing stress in the hospice care environment?

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## INTERVENTIONS AND TECHNIQUES FOR MANAGING PROFESSIONAL STRESS

In addition to the general approaches to stress management that have been outlined above, there are a number of specific interventions and techniques that some individuals have found helpful in managing professional stress. A number of these interventions and techniques are briefly catalogued below.

1. Medical Treatment. Medical evaluation and treatment may be required to ameliorate many of the more severe effects of professional stress. While the medical assessment of stress related disorders is particularly important, one should be aware of the dangers in the use of tranquilizers and sedatives that are often the primary vehicles for the medical treatment of stress.

2. Individual, group, or marital counseling. One of the problematic aspects of professional stress is the difficulty in identifying whether one's emotional turmoil is primarily due to stress in the work setting, to unresolved emotional issues, or to problems endemic to one's personal and social relationships. The services of a psychiatrist, psychologist, social worker, or pastoral counselor may prove helpful in sorting out and addressing the sources of one's personal and interpersonal problems.

3. Career Counseling. Not everyone is emotionally prepared to provide hospice care and many persons may find they cannot work in hospice care for an extended number of years. Utilizing the services of a career counselor may assist us in determining whether we should seek a change in area of specialization or whether we might be more personally satisfied with employment outside the field of nursing.

4. Transcendental Meditation (TM). TM was introduced into the United States in the 1950's by Marharishi Mehesh Yogi and has since received substantial popularity. Proponents of TM describe the benefits of this particular meditation technique as including the increase in one's ability to manage personal and professional stress. TM is being used experimentally in the treatment of stress related illnesses, drug abuse, ulcers, high blood pressure and cardiac conditions (Hemingway, 1975).

5. Benson's Technique. Benson's technique is a simple breathing exercise and meditation technique developed by Herbert Benson of the Harvard Medical School. Detailed instructions on the use of the technique are described in The Relaxation Response (Benson, 1975).

6. Clinically Standardized Meditation (CSM). CSM was developed by Dr. Patricia Carrington. CMS, involves an easily learned technique for meditative relaxation. Detailed instruction on the use of the technique can be found in Freedom in Meditation (Carrington, 1978).

7. Progressive Relaxation (PR). PR is a technique developed by Dr. Edmund Jacobson that involves the progressive relaxation of body muscles to prevent and treat stress and anxiety. The technique is easily learned and is described in Progressive Relaxation and Modern Treatment of Tense Patients (Jacobson, 1929, 1970).

8. Biofeedback. Biofeedback is a technique that utilizes a number of instruments (e.g., electromyograph to measure muscle tension) to provide feedback on a number of complex physiological processes. Through such feedback, its proponents hold that an individual can learn to modify these processes. Advocates of biofeedback recommend it in the treatment and prevention of anxiety and a number of stress disorders (Brown, 1977).

9. Aerobic Exercise Training. Aerobics is a systematic exercise program developed by Dr. Kenneth H. Cooper that is aimed at improving overall health through the strengthening of the cardiovascular system. A number of companies who have discovered the high risks of heart disease and heart attacks among their managers have introduced aerobics as part of their occupational health program (Cooper, 1977).

10. Jogging. Jogging as sport, pastime, and as a technique for stress reduction is currently very popular. Jogging can provide a physical release for pent up stress and tension and can also serve as an excellent time for introspection and reflection.

11. Tension Reduction Exercises. There are a number of tension reducing exercises, such as Tai Chi Chuang and Yoga, that can be effectively used to reduce muscle tension and stress.

12. Assertiveness Training. There are a number of approaches to assertiveness training including the methods popularized by ManUal Smith (When I Say No, I Feel Guilty, 1975). A significant amount of professional stress is exacerbated by our inability to use assertive behavior to set limits, protect our own needs, and avoid being manipulated into positions and roles that we find unbearable. Assertiveness training provides a vehicle to develop and practice assertive communication skills.

These interventions and techniques should be carefully investigated before you select a particular program of stress management. Many of the new stress management programs assure you everything from complete freedom from anxiety to entrance into the promised land. Carefully sift through the sales pitches and decide if a particular technique can be of personal benefit to you.

## B. ORGANIZATIONAL STRATEGIES TO MANAGE PROFESSIONAL STRESS

In this section, we will look at how the hospice organization may inadvertently increase the level of professional stress experienced by the hospice nurse, and we will look at how the organizational environment of the hospice program can be structured to promote the physical and emotional health of the caregiver.

### Organizational Indicators of Professional Stress

Professional stress can have a devestating impact on the health and vitality of the hospice program and can reach a level that the very existence of the program is threatened. In programs where the majority of staff are experiencing excessive levels of stress, we see:

- Frequent tardiness
- Frequent absenteeism
- A high incidence of staff turnover
- Increased interpersonal conflicts between staff
- Scapegoating of individual staff
- Projection of organizational problems onto an outside enemy, e.g., funding source, community, regulatory agency, etc.
- Decreased quality of care to patients

When a significant number of caregivers are experiencing stress related difficulties, we must go beyond our response to individual staff and closely examine the organizational system. We must ask: how are the organizational processes and role conditions within the program contributing to stress related problems? We must ask: In what manner is the program failing to provide adequate professional and emotional support for its staff?

### Organizational Processes that Contribute to the Professional Stress

There are a number of objective conditions (e.g., fiscal insecurity, low wages, staff shortages) in many hospice programs that affect the experience of stress by staff. While the impact of such objective conditions should not be underestimated, there are also subjective conditions (interpersonal processes) that shape the emotional climate of the program and strongly influence the stress response of the caregiver. These subjective factors often prove to be more difficult to identify and more troublesome to rectify.

This author (White, 1979A) has developed a model for looking at professional stress that examines the manner in which internal relationships within an organizational group and the group's relationship with its outside environment effects the physical and emotional health of organizational members. I contend that:

- Health and human service agencies usually approach the problem of professional stress by looking at the personalities of their casualties while failing to look at the organizational processes that contribute to this casualty process.
- An organizational group can be conceptualized as an "organizational family system" based on the assumption that people stay healthy and become dysfunctional in organizations in much the same manner that they do in families.
- Dysfunctional responses to professional stress can be viewed as a breakdown in the relationship between the individual staff member and the organization.
- Dysfunctional responses to professional stress can be viewed as a sympton of system dysfunction in the same manner that emotional problems of individuals can be viewed as a sympton of dysfunction in the nuclear family system.

I have noted the tendency of small health service programs to become "closed" organizational families" and introduced the concept of "organizational incest" to describe the "stage in the life of an organizational group marked by staff meeting most, if not all of, their personal, professional, social, and sexual needs inside the boundaries of the staff group" (White, 1978). Three levels of incestuous organizational closure were described which produce inordinate levels of stress for individual staff. These incestuous dynamics were marked by:

1. The organization of the program around a rigid ideology
2. The director serving more as "high priest or priestess" than program manager
3. The homogenization of staff (often recruited from within the existing social network of the staff group)
4. Program isolation and reduced access to outside professional contact
5. The extrusion of staff who challenge program ideology
6. The projection of program problems on an outside enemy or scapegoating of individual staff
7. Increased interpersonal conflict between staff

8. Staff plots, conspiracies, uprisings

9. The development of a work dominated social network by staff

10. A shift of focus from the care of patients to the personal and interpersonal problems of staff

11. The development of problematic social and sexual relationships between staff that disrupt team functioning

12. A shift from direct communication to gossip and rumor

13. A "loss of faith" in the ideology and a contagion of staff turn-over

These dynamics severely disrupt the delivery of high quality services to patients and are responsible for many of the symptoms of professional stress that we have often erroneously seen as originating from the personalities of individual staff. It was demonstrated that the closed organizational family:

- Produces emotional and physical exhaustion of staff due to excessive time and emotional commitments to support program ideology
- Disrupts the balance between one's work life and one's family, marital, and interpersonal relationships
- Cuts off outside sources of personal, professional, and social replenishment needed to sustain staff in the high stress environment
- Produces intense feelings of being "trapped" since there is no guilt free way for staff to get out of the closed organizational family

While admittedly brief, it is hoped the above description will suffice to demonstrate that there are organizational processes that play a critical role in either sustaining or disrupting the physical and emotional health of individual staff. Those seeking a more elaborate explanation of the systems model of looking at professional stress are referred to the author's monograph, Incest in the Organizational Family: The Unspoken Issue in Staff and Program Burn-Out.

The hospice field may be particularly susceptible to the problems of organizational closure described above. Vachon (1978), for example, has noted that "all too often staff members working in hospice settings become a closed social network, isolating themselves from friendships with others outside the field." The cultural denial of and discomfort with death contributes to the social isolation of those caring for the dying.

The controversies regarding hospice care within the medical and lay communities makes it easy to develop a "them" against "us" posture. The ideological splits within the hospice field contribute to competitive rather than collaborative relationships and may lead to a program's virtual isolation from the rest of the field. Those drawn to the field must have a high level of personal and organizational commitment in the face of frequently unstable funding conditions. These, and perhaps numerous other conditions, increase the tendency for hospice programs to become closed organizational families.

While organizational closure is detrimental to the caregivers, we may discover, in retrospect, that it is even more devastating to the leaders of the hospice field. The emergence of a health care field like the hospice requires a particular kind of leadership, not unlike the leaders that typify most social movements. Such leaders are profoundly commited, seem to have unlimited supplies of personal energy, are exceptionally articulate, and engender a great deal of support through their personal charisma. They are, in essence, organizers and revolutionaries that condemn our current cultural and medical response to the dying and propose a new vision of more humane and responsive care and concern. How then do such leaders respond to their own stress during the years it may take to see their ideas come to fruition? Over time, these leader's professional and social worlds may become smaller and smaller. They may develop small cadres of converts or supporters who uphold their beliefs and offer them ideological support. They may become increasingly disillusioned as they see the "maintainers" coming in to stabilize and standardize the field which the leader played such a role in creating. They may themselves lose touch with the care giving process from which they came. Whether as an intellectual leader in the area of death and dying or as a director of a hospice program, these leaders may creat closed systems in which to insulate themselves. Cut off from outside sources of personal, professional, and social replenishment, the leader must rely on organizational members for support. Their image and charisma, however, makes it difficult for staff to actively provide support, express affection, and provide constructive feedback to the leader. In such virtual isolation, it is little wonder that the leader's ability to function emotionally, socially, and professionally in the field seriously deteriorates. There are debts we all owe to our intellectual and professional leaders. One method of repayment is to help the leader get "out of role" to receive our personal respect and our constructive feedback. Such support may reduce the leader's need for seeking shelter in a closed system that may prove destructive for us all

What subjective conditions or interpersonal processes do you see as contributing to the professional stress experienced within your program?

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## Organizational Role Conditions that Contribute to Professional Stress

In addition to broad organizational processes, there are specific conditions under which a person must perform their role in the organization that contribute to professional stress. The author, in a second study (White, 1979B) identified ten role conditions that produce inordinate levels of professional stress in health and human services workers. Exhibit V-G identifies and defines these role conditions. Three of these role conditions will be briefly discussed for their applicability to the hospice care nurse.

Role/Person Mismatch. One of the mismatches that can can occure in the selection of nurses to work in hospice care results from mistaking someone's willingness and commitment to care for the dying with their knowledge, skills, and emotional fortitude to provide such care. In such a case, the nurse may overcompensate for his or her lack of assurance about the quality of work with an increased quantity of work, e.g., emotional and time commitments. This overcompensation leads to overinvolvement with patients, excessive hours spent on the job, and the eventual physical and emotional exhaustion of the worker. In other situations, the nurse may have many of the basic skills and knowledge to care for the dying, but may find themselves unable to emotionally cope with the continual losses and grieving endemic to hospice work.

We often say it takes a special kind of person to care for the dying and that not everyone is suited for this type of care. To avoid, role/ person mismatch in the selection of hospice care nurses, what attributes would you look for?

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Role Conflict. The nurse may experience role conflict within the hospice program due to simultaneously held roles and responsibilities in patient care, staff supervision, fund raising, staff/volunteer orientation and training, community education, etc. One of the most problemmatic areas of role conflict for the hospice nurse involves the sometimes incongruous demands from the professional role on the one hand and the roles of spouse and parent on the other. Such conflict is particularly troublesome in programs that demand inordinate time and emotional commitments from the nurse. The hospice program may inadvertantly create a situation where the nurse must resign or sacrifice the marital relationship if an unspoken message of "its them (family) or us (program)" is continually communicated.

## EXHIBIT V-G

### ROLE CONDITIONS THAT CREATE OR INFLUENCE THE LEVEL OF PROFESSIONAL STRESS IN HEALTH AND HUMAN SERVICE WORKERS

ROLE/PERSON MISMATCH--the incongruency between: 1) an individual's knowledge and skill level and the skills required to perform tasks of a given role, 2) an individual's level of stress tolerance and the level of stress endemic to a particular role, and 3) an individual's style of stress management and the methods of stress management officially and informally sanctioned within an organization.

ROLE CONFLICT--incongruous demands and expectations from two or more simultaneously held roles.

ROLE INTEGRITY--conflict between personal values and values inherent in the work milieu.

ROLE AMBIGUITY--inadequate knowledge of: 1) role expectations 2) task priorities, 3) methods for task completion; 4) accountability structure, and 5) rewards and punishments.

ROLE FEEDBACK--the availiability of regular information on 1) adequacy of role performance, 2) methods of improving performance, and 3) adequacy of adjustment to work milieu.

ROLE OVERLOAD--excessive and unrealistic expectations regarding quantity of work to be completed within given time frames.

ROLE BOUNDARY POSITION--the misplacement of staff with skills in interior program positions into boundary positions, e.g., clinicians promoted to administrators.

ROLE CONNECTEDNESS--One's degree of isolation or overconnectedness to other program staff.

ROLE DEPRIVATION--the sudden or gradual removal of all significant responsibilities from an individual--forced retirement on the job.

ROLE TERMINATION--failure to provide permissions, procedures, and processes to allow staff guilt free exit from the organization.

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Role Connectedness. There are two potential problems for the hospice nurse related to role connectedness: an overbonding to other staff at one extreme and the relative isolation from other staff at the other extreme. The problem of isolation is particular relevant to the nurse providing home care. The home care nurse is always on foreign territory (and on occasion in very unpleasant physical settings), experiences the same stress in the care of the dying as the inpatient nurse, but does so without many of the support systems available to the inpatient nurse.

Review the 10 role conditions presented in the chart. List those role conditions you most frequently experience.

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List the role conditions most prevalent within your program.

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## Organizational Strategies for Managing Professional Stress

There are a number of administrative strategies that can be developed to enhance the nurse's response to professional stress within the hospice program. These strategies, in general, seek to maintain the openness of the organizational system, decrease role stress conditions and increase role supports. A systematic approach to professional stress includes influencing the manner in which the nurse enters the hospice program, building in ongoing support mechanisms, and influencing the manner in which the nurse leaves the hospice program. Each of these areas will be briefly discussed. Those seeking a more indepth discussion are referred to the author's monograph, A Systems Response to Staff Burn-Out (White, 1978)

## Hiring and Orientation Within the Hospice Program

To avoid role/person mismatch, great care should be taken in the selection and hiring of nurses for hospice care. Each program should develop its own selection criteria based on the knowledge, skill and emotional demands of the particular setting. Special cognizance should be made of the special skill and emotional demands placed on the nurse providing home care and for those dealing exclusively with special patient populations, e.g., children. The importance of this stage is the recognition that the program's responsibility and sensitivity to the issue of professional stress begins at the screening and selection process.

We discussed earlier the "reality shock" that may be experienced by the nurse moving from the traditional nursing role to that of the hospice care nurse. This reality shock can be significantly reduced through the provision of a formalized orientation program for the incoming nurse. The nurse's knowledge and skill deficiencies should be quickly identified so that training activities can be provided to offset the nurses concern with professional adequacy in the hospice setting. Part of the orientation and training program should focus on the issue of professional stress. Supervisory and professional supports should be quickly defined and great emphasis should be placed on the nurse's ability and need to seek social and emotional replenishment in his or her personal life.

## Ongoing Supports Within the Milieu of the Hospice Program

A number of ongoing support mechanisms for the hospice nurse are briefly discussed below.

A. Review the employee benefit package. Are salaries and benefits commensurate with knowledge, emotional, and time demands? Are there sufficient time out periods provided for i.e., vacation, sick time, compensatory time, personal or mental health days? Does the program provide support for continued education and training of nurses? Are there provisions for half time employment or leaves of absence? Does the insurance cover treatment of emotional disorders, alcohol abuse, and other disorders that may be stress related?

B. Is there an employee assistance program to assist the nurse whose physical or emotional problems may be affecting their performance in the work setting? The existence of such a program and the staff's knowledge of its workings are an important organizational response to the problem of professional stress.

C. What are the provisions for the continuing education and training needs of the hospice care nurse? Inservice and offsite training, continuing education and degree work, participation in professional organizations, etc. can all serve to decrease the nurses vulnerability in the provision of hospice care.

D. Is there a support group available to the hospice care nurse? Many hospice programs have made support groups for staff an integral part of the care process. These support groups, often facilitated by an outside consultant, provide for the ventilation of feelings and mutual support by caregivers. These groups also provide one setting in which the nurse can express his or her grief, and provide a setting to continue to explore our feelings and values regarding death.

E. Is there physical space in the program where the nurse may periodically go for shelter from the intensity of the caring process? Such a space clearly recognizes the need for the nurse to periodically take time out during the day for rest and emotional replenishment.

F. Are there mechanisms to address the isolation of the home care nurse? Increased supervisory supports may be needed to sustain the home care nurse. Some supervisors have found it helpful to meet the home care nurse in the field for lunch, particularly on days the nurse anticipates a number of emotionally draining experiences with patients and their families. It may also prove beneficial to have two persons provide home care as a team, at least with the more difficult patients.

G. What mechanisms have been developed to assist the hospice nurse with the potential strain on his or her family relationships? In a recent HCS, Inc. survey of hospice care nurses, 84 per cent of the respondants reported that their work in hospice care had at times placed a strain on their personal and family relationships. It appeared that one problem was the difficulty of family members in understanding the nature of hospice care and the emotional demands upon the nurse. Developing an orientation program for the families of the hospice nurse might prove particularly helpful in addressing this problem. Equally important is the necessity of the program to establish realistic time demands of the nurse and generally respect the boundary between the nurse's personal and professional lives.

H. Is the program assisting the nurse in increasing his or her personal vulnerability to professional stress? Managing stress is an acquired skill that very few of us have had formal training in. Providing the hospice care nurse with stress management training and the sanctioning of stress management strategies and techniques within the work setting are exceedingly important organizational responses to the problem of professional stress.

I. All of us need to know that our work is important, that we are providing competent and sensitive care to the dying, that our work is appreciated, and that we have the respect of our professional peers. We may fail, however, to adequately express our affection and respect for one another. Mechanisms can be developed to enhance such stroking behavior between staff e.g., modeling of supervisory staff, support groups, etc. within the program.

J. Given the emotional intensity of the work, it is perhaps inevitable that periodic conflicts will occur between members of the interdisciplinary team. Developing mechanisms to rapidly resolve such conflicts is critical to shaping an emotional climate that reduces the professional stress of the hospice care nurse.

## Allowing the Hospice Nurse Guilt Free Exit From the Program

Many hospice care nurses will for personal or professional reasons eventually choose to leave the particular hospice program in which they work. This may be to accept another professional position within or outside the hospice field, retirement, etc. It is very important that we allow persons to leave our programs with a sense of personal fulfillment and completion. When this termination process is not handled properly we see a high level of stress and guilt experienced by the nurse leaving, emotional turmoil within the interdisciplinary team and fragmentation in the transfer of the nurses responsibilities. Facilitating the termination of staff in a manner that provides minimal personal and program turmoil involves:

- Providing staff guilt-free permission to leave the program for personal or professional reasons

- Providing procedures to facilitate the smooth transfer of the person's responsibilities

- Providing processes and rituals for the interpersonal separation (White, 1978B)

What additional programmatic strategies could assist the hospice nurse in managing professional stress?

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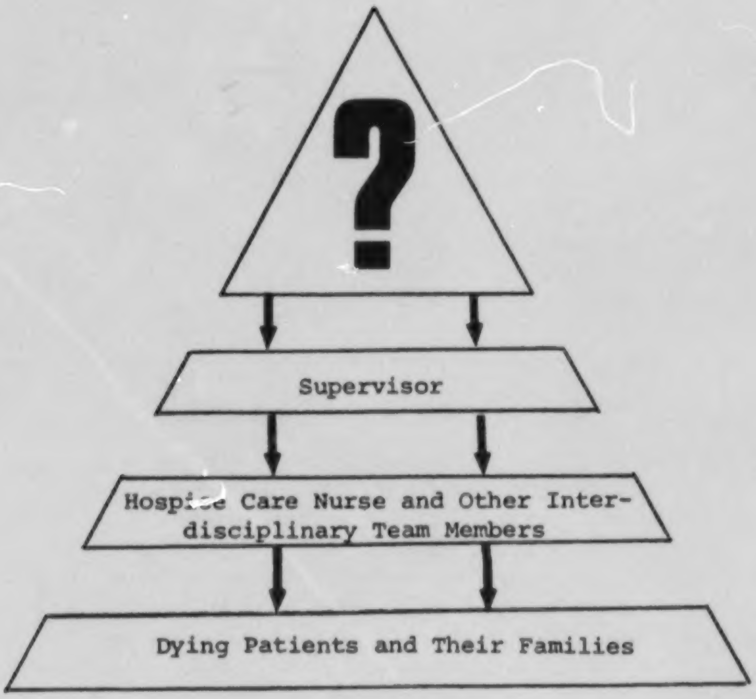
## C. SUPERVISORY RESPONSES TO VICTIMS OF PROFESSIONAL STRESS

It is common for the nurse to hold key supervisory positions within hospice care programs. This supervisory role may involve the nurse in such diverse role functions as teacher, trainer, consultant, advocate, supporter, administrator, conflict resolver, and evaluator in relationship to other members of the interdisciplinary team. Within the context of these supervisory functions, the nurse may play a critical role in the reduction and alleviation of professional stress. In this, the final section of Module V we will look at how the nursing supervisor, may respond to victims of professional stress within the hospice care environment.

### Taking Care of Oneself as a Prerequisite for Supporting Others

There ideally exists a chain of support that exists within the hospice care program. This chain of support is graphically displayed in Exhibit IX-H.

## EXHIBIT V-H: CHAIN OF SUPPORT WITHIN THE HOSPICE ENVIRONMENT


?
Supervisor
Hospice Care Nurse and Other Interdisciplinary Team Members
Dying Patients and Their Families

In this model we see the dying patients and their families supported by members of the interdisciplinary team who are in turn supported by the supervisor. At this point in the chain of support, the question emerges as to who supports the supervisor. The issue being raised is a theme that has continued throughout Module V -- namely, that one cannot continue to provide emotional support to others without sources of emotional support and replenishment for oneself. The supervisor's first responsibility is thus to utilize personal and professional supports to manage their own stress. This allows increased openness to the problems and concerns of staff and provides a model for personal stress management to other members of the team.

What professional sources of support could be best utilized by the supervisor in the hospice setting?

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## Ongoing Supervisory Responses to Professional Stress

The nurse who functions in a supervisory role within the interdisciplinary hospice care team can play a critical role in shaping organizational responses to professional stress in the care of the dying. The following suggestions are offered to the supervisory nurse as ongoing responses to reduce the severity of such professional stress.

1) Stay abreast of current information and literature on the nature of professional stress in the care of the dying. As the field evolves, greater attention to and understanding of this phenomenon will emerge that will allow for the development of increasingly sophisticated support systems for the hospice care professional.

2) Clearly define both the content (what does supervision mean?) and the procedural aspects of supervision (when and where does supervision occur?) for those under your direction. Defining the nature of supervision and your accessibility provide the boundaries and framework through which staff can seek support. The parameters of this supervisory process should range from the provision of task oriented directives and feedback to providing staff permission for affective expression regarding their experiences caring for the dying patient and their family.

3) Recognize that you are one of the most important sources for personal and professional strokes within the program. Consciously work on your ability to acknowledge and praise staff for their individual skills and abilities.

4) Practice your skills at providing effective feedback to staff on their work and their overall adjustment to the work milieu. Some general suggestions on the nature of useful feedback include the following:

- It is descriptive rather than judgemental. Useful feedback focuses on behavior (what the person did); it does not focus on the nature of someone's character (what the person is).

- It is specific rather than general. Talking to someone about their behavior with a particular patient in a specific situation is more effective than discussing the person's "attitude problem".

- It protects the self esteem of the recipient. Observing that someone could expand their patient care skills by experimenting with more physical contact and "silent time" with patients is more effective than reporting that someone "talks too much" and is "too dominating".

- It is directed toward behavior that the person can do something about.

- It is well timed. Feedback is most useful when provided as soon as possible to the time the behavior of concern occurred. Timing also depends on the recipient's readiness to hear and understand the feedback.

- It is checked to ensure that the receiver has accurately understood the communication.

- The receiver is given opportunity to check the accuracy of the feedback with other staff in the program.

- Feedback is best received when given out of concern, interest, and respect for the recipient.

5) Confront early warning signs of professional stress. Let your supervises know when you observe signs that indicate stress may be effecting their work performance or their physical and emotional health. Many of us are oblivious to such early signs and must rely on persons who care about us to let us know a problem may be developing.

6) Confront overproduction. Help staff set and enforce realistic limits on the number of hours per week they will work within the program.

7) Be aware of how changes in the personal lives of staff influence their vulnerability to professional stress. You may need to temporarily increase supports and reduce the work demands upon staff experiencing sudden and inordinate levels of stress in their personal lives.

8) Provide a tighter time structure (schedule of supervisory contact) for staff whose roles tend to isolate them from other program staff, e.g., home care nurses.

9) Periodically reflect on those conditions in the work environment that may be exacerbating the levels of stress experienced by staff. Advocate for

and involve staff in a process to alleviate such conditions.

10) Utilize both staff meetings and individual time with supervisors to respond to the anticipatory grief, grieving, and accumulated grief of staff.

What other ongoing supervisory response do you see as important in reducing the level of professional stress in hospice care staff?

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## Responding to Individual Victims of Professional Stress

In spite of our best efforts to prevent the debilitating effects of professional stress in the care of the dying, the supervisor will periodically encounter an individual staff person or volunteer whose job performance and physical and/or emotional health has deteriorated from the impact of stress in the work environment. How then does the supervisor respond to these individual casualties of professional stress? In the brief discussion that follows, we will examine three stages in the supervisory response to victims of professional stress:

- Recognition and acknowledgement
- Assessment and identification
- Intervention

Responding to a supervisee's deteriorating job performances is one of the most difficulty tasks for the supervisor. There are numerous factors that make it easier for the supervisor to deny the existence of a problem. The supervisor often has had a long standing relationship with the supervisee that makes it difficult to openly confront and acknowledge that the quality of the supervisee's work has gone through a marked change. It is easy for the supervisor to assume that performance problems are transient and will "work themselves out". This tendency toward denial must be overcome and the supervisor must directly and honestly facilitate the recognition and acknowledgement of a problem by the supervisee. The focus of this dialogue must be on the supervisee's job performance.

Once there is mutual recognition of a problem by the supervisor and supervisee, the exact nature of that problem can be further defined. Some programs may have formal employee assistance programs that can be utilized for this assessment; in others this area will be the sole responsibility of the supervisor. The model we have used in Module V to understand the nature of one's stress response can provide one framework for this assessment. In this framework we examine the roles of personal vulnerability, organizational context, and specific stressors in the persons performance problems. The importance of this assessment stage and another model for conducting such an assessment have been described by the author in an earlier monograph:

> "Assist the staff person in identifying and labeling the problem. Give the staff person some words he or she can use to describe what is happening to them. Many persons suffering from the high stress work environment have not identified this as the source of their turmoil and simply fear they are going crazy. Identifying and labeling work related stress can in and of itself free up energy of staff to begin to remobilize their personal resources.
>
> I have utilized a model of assessing work related stress that is similar to methods used to assess family systems. I explain to the staff person that if staff are to function optimally in delivering client services, each staff person has three areas of needs that must be regularly met. (1) Each staff person has personal needs that must be met outside of and totally separate from the program. (2) Each staff member has needs that must be met in their professional peer relationships. (3) Each staff person has needs that must be met in their relationships with clients. I explain that anytime all of these three need areas are not met, particularly when one area is met at the exclusion of the other two, there is a decrease in functioning both personally and professionally. The staff person and I then assess these three areas of the person's life to identify areas of neglect and personal dissatisfaction. The goal is to re-establish balance between the three areas. It should be emphasized that this assessment and problem identification process is done by not looking at the personality of the staff person, but by looking at the breakdown of supports between the staff person and the work system. The problem is defined as interactional, not intra-psychic. The assessment is to identify ways the system can be manipulated to reduce over-extension and produce nourishment for the staff person; it is not a diagnostic interview to enlist the staff person into "treatment" with the supervisor". (White, 1978B)

Supervisory responses to victims of professional stress generally fall into the following three categories:

1) Interventions to respond to the immediate needs of the supervisee, e.g., immediate medical/emotional problems, need for a time out period from the work environment, support of the person's personal defense structure, supporting enhancement of stress management skills, etc.

2) Interventions to reduce stressful organizational processes and role stress conditions

3) Interventions to increase personal and professional supports

Within the above strategies, it is probably most important that the supervisor firmly and consistently reinforce the following three messages to the victim of professional stress:

1) High levels of professional stress and grief are inevitable experiences for those persons who work intensively with dying patients and their families. (You are not alone!)

2) You can recognize and manage this professional stress and grief before it produces irreversible impairment to your physical and emotional health. (You can take control!)

3) You can make clear decisions and take actions that produce the nourishment necessary for you to re-energize and re-establish the balance in your personal and professional life. (You can regain potency and health!)

What other supervisory responses to victims of professional stress do you see as important?

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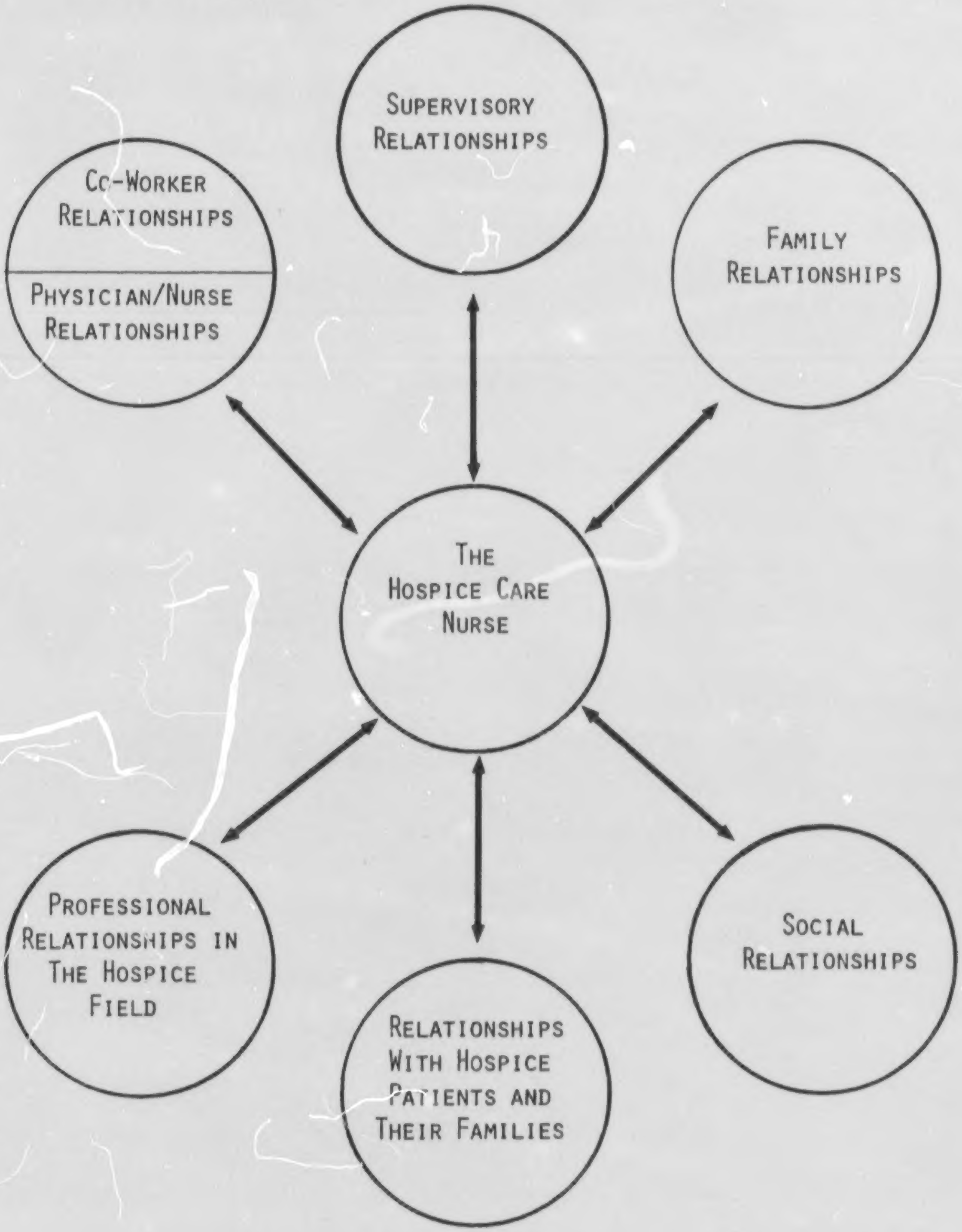
## D. SUMMARY

Module V has focused on managing personal and organizational stress in the care of the dying. The module:

- Identified personal and organizational factors that contribute to the professional stress of the hospice nurse
- Examined personal strategies and techniques for managing stress in the work environment
- Explored organizational and supervisory strategies to reduce the level of professional stress experienced by those caring for the dying

A theme that has permeated the entire module is that both the experience of professional stress and the alleviation of that stress takes place within a network of relationships. As Exhibit V-I illustrates, the provisions of hospice care is done within a relationship network-each component of which

## EXHIBIT V-I
## STRESS AND THE RELATIONSHIP NETWORK OF THE HOSPICE CARE NURSE


SUPERVISORY RELATIONSHIPS
CO-WORKER RELATIONSHIPS
PHYSICIAN/NURSE RELATIONSHIPS
FAMILY RELATIONSHIPS
THE HOSPICE CARE NURSE
PROFESSIONAL RELATIONSHIPS IN THE HOSPICE FIELD
RELATIONSHIPS WITH HOSPICE PATIENTS AND THEIR FAMILIES
SOCIAL RELATIONSHIPS

may serve as a source of stress and/or a source for the mitigation of professional stress.

The most critical element in the remediation of professional stress is the existence of a relationship network that can provide sources for the personal, professional, and social replenishment for the hospice care nurse.

It is the author's hope that the learning experiences in this module will further enhance your ability to provide high quality care to dying patients and their families, while protecting your own physical and emotional health.

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# MODULE VI: UNDERSTANDING OF THE PROCESS OF DYING AND THE DEATH EVENT ITSELF

PARTICIPANT MANUAL

DEVELOPED BY:

Ida M. Martinson, R.N., Ph.D.

# MODULE VI: UNDERSTANDING OF THE PROCESS OF DYING AND THE DEATH EVENT ITSELF

## PURPOSE AND GOALS

The purpose of Module VI is to increase the nurses' understanding of the process of dying and the death event itself. The goals of the module are to assist trainees to:

- Identify and operationally define the major physiological mechanisms of dying
- Develop a basic understanding of the signs and symptoms which may be seen in the dying person
- Identify the death event
- List nursing measures appropriate to the presenting signs and symptoms

## MODULE CONTENT

The module content includes the following areas:

- Historical review of the signs and symptoms of the dying process and death event
- Operational definition of dying and the death event
- Physiological indicators of dying and death on the cellular and system-wide level
- Impact of the breakdown in the cardiovascular system on physiological functioning, including the effect on the respiratory system
- Impact of brain and central nervous system involvement on physiological functioning
- Effect of bowel obstruction, constipation and incontinence
- Physiological results of hemorrhage, liver dysfunction, weight loss and anemia
- Process of starvation and dehydration
- Effects of the muscular system and other common signs and symptoms during dying
- Physiological changes following death

## LEARNING OBJECTIVES

As a result of successful completion of Module VI participants will be expected to demonstrate their ability to:

- Define physiological death and dying in relationship to historical and current multidisciplinary interpretations of dying and death
- Demonstrate an awareness of similarities and differences between cell death and somatic death, utilizing examples representing a terminal disease, such as cancer
- Understand the important physiological interrelationship between failure of the heart, lungs, and brain and the process of dying
- Describe specific physiological crisis events which most frequently occur during the dying process
- Explain the nurse's role immediately following a home death, in view of predictable physiological postmortem changes, as well as anticipated family support needs
- Evaluate the most important nursing measures concerning home care for terminal illness in view of predictable physiological aspects of the dying process, as well as appropriate symptomatic care

# MODULE OUTLINE

## SECTION A: PHYSIOLOGICAL CHARACTERISTICS OF DYING AND DEATH

I. Overview:

A. Historical Definitions
B. Current Approaches
C. Definitions Underlying the Present Discussion
D. Cancer: A Case Example Demonstrating Physiological Symptoms of Dying and Death

II. Physiological Signs and Symptoms of Dying and Death

A. Cellular Functioning and Malfunctioning

1. Normal Cellular Function
2. Death of Cells
3. Pacemaker Cells

B. Physiological Changes During Dying

1. Regulatory Mechanism
2. Three Organ Systems Associated With Life or Death

a. Cardiovascular
b. Central Nervous System
c. Respiratory System

C. Physiological Changes Following Death

## SECTION B: SYMPTOMS AND SYMPTOMATIC CARE CONCERNING DYING AND DEATH

I. Signs and Symptoms Preceding Death

1. Changes in appetite and taste
2. Nausea
3. Bowel obstruction
4. Incontinence
5. Constipation
6. Weight loss
7. Anemia
8. Bleeding
9. Cyanosis
10. Dyspnea
11. Respiratory distress
12. Seizures
13. Skin changes
14. Bone tenderness
15. Muscle dysfunction
16. Mouth and jaws - appearance
17. Renal insufficiency
18. Liver malfunctioning
19. Pneumonia
20. Environmental effects

II. Summary: Physiological Changes and Appropriate Intervention Preceding Death

III. Nursing Support of Family Immediately Postmortem

# SECTION A
# PHYSIOLOGICAL CHARACTERISTICS OF DYING AND DEATH

## I. OVERVIEW

### A. Historical Definitions

In the past, few difficulties existed in defining the concepts of "dying" and "death" with clear and simple explanations commonly accepted by all. For example, Hippocrates (*The Genuine Works of Hippocrates*, 1840:236) referred to the process of dying by observing that "signs of the worst" were "a sharp nose, hollow eyes, collapsed temples, cold contracted ears with the lobes turned out, forehead skin rough, distended and parched, and a green, black, livid or lead coloring of the face." The event of death was further described as "when the eyelids were contracted, livid or pale; the lips and nose livid or pale; and the other signs prevailed, then death was close at hand. The 'mortal sign' was relaxed, pendant, cold or blanched lips."

Later Munk (1887:55) offered a description of "dying persons" by utilizing similar anatomical descriptions; but varying the number, combination, and order of appearance of the specific characteristics. For example, "Signs of the dying act" were described as including glazed, half closed eyes; dropped jaw with open mouth; blanched, cold, and flaccid lips; cold, clammy sweats on the head and neck; hurried, shallow respirations or a slow, stertorous breathing with a rattle in the throat; irregular, unequal, weak and immeasurably fast pulse; position supine sliding down toward the foot of the bed; arms and legs extended, tossed about in disorder; and hands waving in empty air, fumbling and picking.

### B. Current Approaches

Contemporary attempts to define "dying" and "death" have become increasingly complicated with varying, and sometimes conflicting, interpretations arising from differing disciplinary approaches, especially in the disciplines of law, theology, biology and clinical medicine. Adding further complexity is the fact that health professionals tend to focus upon different dimensions when defining these concepts.

For example, several studies have emphasized changes in the circulatory system to describe the dying process. Garvey's (1952:31) investigation utilized such vital signs and other circulatory indicators as a rise in pulse, a fall in blood pressure, a rise or fall in oral temperature, a rise in rectal temperature, periodic or Cheyne-Stokes respirations changing to grunting and rattling, cold extremities, pallor and mental cloudiness. Mottled skin and cyanotic lips and nails attributed to a reduced blood supply were signs seen by Walker (1973) during the last hour before death. Lewis (1965) claimed a slowed circulation predisposed the patient to complications. A decrease in peripheral circulation during the dying process was acknowledged by Worcester (1940:39). To this he attributed a drenching sweat and a cooling of the body surface, regardless of the temperature of the surrounding air. The sweat was described as most profuse on the upper parts of the body and on the extensor rather than the flexor surfaces. As the surface cooled, the inward temperature increased instead of lessening. Kirk (1968) viewed the terminal phase as resembling shock, except that in shock, the person retained a certain degree of consciousness. His description of clinical signs emphasized a rise in temperature and pulse, a fall in blood pressure, pallor, hollowed cheeks, pointed nose, dry tongue, dull corneas, sunken eyes, a cold sweating forehead, a loss of consciousness, a decrease in muscle tone so that the jaw sags and the mouth opens, and audible, rattling breathing going to shallow, inaudible, to Cheyne-Stokes respirations.

While recognizing circulatory changes, others have also commented on additional aspects, such as muscle dysfunction. For example, Worchester (1940) noted that dying is a progressive process, usually proceeding from the feet toward the head resulting in the sensation of losing power of motion and reflexes, first in the legs and eventually in the arms. In addition, anal sphincters relax, peristalsis ceases and the stomach distends before the patient can no longer swallow. Thus, sucking and breathing are the last instinctive actions and thirst the last craving.

Additional dimensions of dying have been explored by Rodstein and Borstein (1970) who revealed the electrocardiogram pattern of the dying heart, and Exton-Smith (1961) who documented geriatric patients' perceptions of such symptoms and discomforts as pain, nausea, vomiting, dysphasia, dyspnea, confusion and awareness of dying. In addition Carrington (1921:90) focused upon the smell associated with the dying process. The so-called smell of death was described as the smell of musk, the source of which was claimed to be the development of ammonia in decomposing blood. Although the source is unknown, nurses have also reported a characteristic smell associated with the dying patient's room.

Dying has been described by research sociologists as a process with a well defined temporal course. Strauss and Glaser (1970) refer to this process as the "dying trajectory." Trajectories which are perceived, rather than actual courses of dying, have duration and shape. Acute deaths are quick, while unexpected deaths exhibit short, sharp trajectories. Expected deaths are anticipated, lingering deaths are perceived as having longer, blunt trajectories.

Finally two comparative studies have revealed further insights, such as Rees' (1973) comparison of those dying at home with those dying in the hospital and Hinton's (1963) historical comparison of the physical discomforts and mental status of dying patients with patients seriously, but not fatally, ill.

### C. Definitions Underlying the Present Discussion

While there are many ways one could approach a discussion of death and dying, the material that follows will focus on the physiological and biological aspects of dying. As such, "dying" will be defined as a series of irreversible biological overtime events, (which precede death) experienced by patients not expected to recover (Shusteman, 1973). The outcome of the dying process is "death," which more precisely is a cumulative cell death which culminates in somatic death.

Somatic death, or death of the body as a whole, is defined as a cessation of the functioning of vital organs--the heart, lungs and/or brain. With the collapse of any one of these vital organs, cell death rapidly proceeds, although unevenly, in the rest of the body, resulting in cessation of cell life throughout the entire organism. Rapid somatic death is said to occur most often when cardiac functioning ceases. A number of serious events follows the cessation of heart beat, e.g., a fall in temperature which leads to cooling and stiffening of the body, clotting of the blood, discoloration of tissues and structural and functional changes in red blood cells. Muscular structure and chemical changes also occur resulting in muscular rigidity and eventually autolysis of tissues. Similarly, failure of brain and lung function is equally destructive. Malfunctioning of these three organ systems and how they relate to somatic death will be explored more fully in the following section.

Whenever cell death occurs, there is a termination of the functions of individual cells, or groups of cells. Sometimes a particular vital activity comes to a halt before others. For example, the heart may continue to beat for a short time after respiration has stopped. Also, when cellular respiratory mechanisms are destroyed other activities may continue briefly. Disassociation of vital function at the cellular level makes it extremely difficult to be certain of the precise moment of cell death. In other words, cell death can occur without somatic death and somatic death can occur with cells continuing to live for short periods. The system does not fail all at once and organs stop their operations at different modal rates, and possibly even at differing rates for each individual. Further investigation of cellular functioning and malfunctioning immediately follows this "Overview."

### D. Cancer: A Case Example Demonstrating Physiological Symptoms of Dying and Death

While a paucity of information exists clearly identifying subjective and objective indicators of the dying process, respiratory and cerebral cell death is recognized as an absence of respirations and/or brain waves, respectively. One example of the dying process and the outcome of death has been documented by Inagaki, et. al. (1974) in studying the incidence of infection, organ failure and hemorrhage, as revealed during autopsy of cancer patients. This study concluded that:

> "Infections in our patients were mostly due to the mechanical or pathological effects of the underlying malignancies. Although more vigorous antibiotic therapy is needed before

> adequate control of these complications can be accomplished.... Twenty-five percent of the patients in this study died from organ failure which was usually caused by the underlying malignancy. Other factors producing organ failure in these patients were mainly arteriosclerotic in origin and occurred in the elderly population. Iatrogenic liver and renal failure were rarely seen as a terminal event.... The incidence of hemorrhage as the terminal event in leukemic patients has significantly decreased since the introduction of platelet transfusions. In our study fatal bleeding occurred in only 7% of the patients and was mainly related to tumor factors.... Finally in a group of 83 patients with advanced disease, a specific cause of death could not be determined. All these patients had extreme degrees of debilitation, malnutrition, and electrolytic imbalance which led to death. At postmortem examination, their malignancy was disseminated to almost all vital organs and consequently they were considered as dying of 'carcinomatosis."

Since cancer has been identified as among the major cause of death, this particular disease will be utilized to discuss some of the signs and symptoms of dying and death. Data underlying the present discussion is based upon reports of physiological changes reported during dying, as well as autopsy reports following death from cancer.

## II. PHYSIOLOGICAL SIGNS AND SYMPTOMS AND MALFUNCTIONING

### A. Cellular Functioning and Malfunctioning

### 1. Normal Cellular Function

Normal cellular function includes four basic activities:

- The production of energy required for vital cellular processes, the energy that makes the cell work
- The production of both enzymatic and structural protein
- The maintenance of the chemical and osmotic homeostasis of the cell
- Cell reproduction

The ultimate cause of cell death is the derangement of one or more of these vital functions.

## 2. Death of Cells

Cell death results from a combination of influences. It is becoming increasingly clear that dying does not induce general cellular changes equally throughout the body, either on a morphological or biochemical level. Rather, the type and severity of the changes, consequent to dying, appear to vary considerably from cell to cell, as well as from tissue to tissue, within the same organism. In other words, dying of the cell may be ascribed to alterations in the setting of the control mechanism that regulates the functional activity within and between cells.

Six ideal conditions are necessary for energy production in the cell. These are: 1) adequate amount of A.D.P.; 2) adequate amount of inorganic phosphate: 3) balanced nutritional substrates including calcium; 4) adequate oxygenation; 5) a steady state of activity; and 6) an intact membrane system.

Adequate amounts of A.D.P. and inorganic phosphate not only influence energy production, but they are thought to be the actual controlling mechanisms for A.T.P. production.

It has been noted that energy production is dependent on the conversion of food (fuel) energy into high energy phosphate storage compounds .... The maintenance of adequate stores of these compounds depends on the metabolism of ingested foods. Biosynthesis is the very essence of the living state, including not only formation of characteristic chemical components of cells from simple precursors, but also their assembly into structures such as membrane systems, mitochondria their nuclei and ribosomes, as well as specialized structures that characterize highly differentiated cells such as found in muscle, nerve and kidney. The large macromolecules of the cell are assembled from very simple precursors by sequences of enzymatic reactions utilizing A.T.P. as their energy source. Adequate nutrition is necessary, therefore, not only for energy but also for the very existence of the cell and its organelles via biosynthesis.

Physical activity performed on a regular basis will improve the rate of oxygen consumption which depends on: 1) the amount of oxygen in the air; 2) the condition of lungs; 3) the adequacy of pulmonary perfusion; 4) the ability of the cardiovascular systems to transcript oxygenated blood to the cells; and finally 5) the diffusion of oxygen from the capillaries to all the mitochondria.

Two things are required for the maintenance of functional cellular and subcellular membrane systems: 1) There must be the continuous biosynthesis of the protein, liquids and other components to replace those being broken down because of wear-out/damage; 2) There must be protection of the membrane system, as much as possible, from the external hazards which are known to cause membrane damage and/or uncoupling of oxidative phosphorylation resulting in no A.T.P. regeneration.

The cell is viewed as a dynamic, equilibrated microcosm in which loss of some of its power sources results in a temporary or permanent loss of some of its energy and, consequently in one of its functions. Cumulative loss of cell function leads eventually to cell death and continued loss of cells will impair tissue and organic functioning, resulting ultimately in death of the organism.

The capacity to adapt to an ever changing environment is fundamental to all living organisms. It may well be that in the dying process this capacity is decreased. The human being then is no longer able to maintain itself and begins to reflect the environment or the situation in which the person exists.

### 3. Pacemaker Cells

The pacemaker cell functions with the help of nerves and hormones and is responsive to changes in the physical or chemical environment. Other cells act as pacemakers only under special situations. Many other cells are completely dependent upon other factors for stimulation. The role of the nervous system is to integrate these diverse cells to meet the needs of the organism--specifically, to first maintain a fairly constant internal environment, which is called homeostasis, and secondly to assist in regulating an almost continuous blood supply to the heart and brain.

## B. Physiological Changes During Dying

### 1. Regulatory Mechanisms--Normal and Pathological

The regulatory mechanisms concerned with efficient and effective body response at any level of biological organization are vital to the overall functional competence of the individual. The nervous system and the endocrine system play major roles in regulating and integrating the relationship of organisms to the environment. Both systems are crucial in keeping our physiological system functioning in a coordinated manner. However, rather than discussing the endocrine and nervous system in this unit, emphasis will be placed instead on the cardiovascular and respiratory systems, as well as some life regulating survival functions of the brain. This focus will produce a clearer understanding of the overt signs and symptoms accompanying the dying process. Progressive alterations in homeostasis from health to death may occur. In a healthy adult, compensatory processes ensure adequate adjustment in response to various stresses. Compensatory processes serve to maintain overall function without serious disability. However, when stress goes beyond the capacity of the organism to adapt, death will result.

### 2. Three Organ Systems Associated With Life or Death

While theories on the nature of the dying process are not numerous, and dying is not a simple discreet phenomenon but rather a series of complex inter-related cellular changes which occur over time, much of what is known of the dying process is related to the disease processes. Much has yet to be learned, however, concerning cellular transformations associated with dying from a disease, such as cancer, as opposed to those associated with dying which has resulted from aging.

In an attempt to further explore the process of dying from disease the following will focus upon the three main mechanisms of dying, that is failure of the brain, heart, or lungs. Simply stated, the series of events leading to death are:

- The brain ceases to supply information vital for controlling ventilation, heart action or muscular tone of arteries

- The lungs are unable to supply adequate fresh air for gas exchange with the blood stream
- The heart or blood vessels are unable to maintain adequate circulation of blood to vital tissues

Prior to recent medical technological advances, the heart, lungs, or brain frequently failed in a rapid synchronous manner, regardless of which was initially mortally affected. Current technology can support the cardiopulmonary functions for long periods of time maintaining cerebral performance, thus rendering inconsequential the temporal order of organ failure. While the original intent of this life support technology was to maintain the functioning of these organ systems during a period of crisis, from which recovery might otherwise be expected, the utilization of such means to support vital functions in terminal patients regardless of age or disease may become inappropriate.

### a. Cardiovascular System

Proper circulatory function is maintained by a delicate balance between cardiac output and the venous return of blood to the heart. Cardiac output is the quantity of blood pumped each minute from either the right or left ventricle into its respective circulatory bed and is calculated from the product of the heart rate and the stroke volume. Venous return of blood to the heart regulates cardiac filling and therefore the amount of blood available to be pumped. Thus, the cardiac or circulatory cycle continues. Six factors (gravity, skeletal muscle activity, venous motor tone, venous valves, respiratory activity and cardiac contraction) facilitate venous return. All of these factors aid to keep the balance between cardiac output and venous return. Blood flow, as determined by cardiac output is responsible for the transport of necessary nutrients, waste materials, gases, hormones, and hormonal factors, to and from all the cells of the body. Without blood flow there is no life.

When blood volume is reduced, as in hemorrhage, this condition is referred to as "hypovolemia." In this condition venous pressure falls and venous return to the heart may be inadequate. The body attempts to compensate by increasing venous motor tone, which decreases the capacitance of the venous system and its distensable bed, resulting in an increased venous pressure.

During the dying process the heart as a pump can fail and all cells of the body are affected by insufficient blood flow resulting in ischemia. The heart is the organ responsible for blood pressure and flow of blood to the rest of the body. The highly elastic arteries store some of the energy produced by the heart during systole and release it during diastole, thus giving a fairly constant blood flow to the tissues of the body. Distribution of blood is accomplished by the arterioles. When an artery increases its muscle tone, blood flow to the area served is decreased. When smooth muscle relaxes, blood flow is increased. It is possible to increase blood flow to all parts of the body at once by increasing cardiac output. It is also possible to maintain a constant cardiac output and increase blood flow to another part by local arterial relaxation. This complex system is controlled by both the sympathetic and parasympathetic nerves to the heart and sympathetic fibers to the arterioles. Blood flow is thus regulated by stretch, circulating hormones, and various oxygen concentrations in the blood. For example, it is vital that blood to the brain be maintained. Because of the important role of the brain including the role in respiration, it must receive oxygen or will suffer permanent damage. The human circulatory system is arranged so that there is preference given to the brain. This built-in system ensures that if other parts of the body do not receive blood, the brain does. Therefore, although pooling of the blood may occur, collecting in the viscera, still blood may continue going to the head. This could possibly account for the alertness that precedes death for some individuals, although they have not been alert, even comatose. Before death, somehow through the return of the blood to the heart,more blood may go to the brain, stimulating alertness at the time preceding death.

The heart is the major pump for the circulatory system; disease or injury weakens the pump, resulting in inability to provide force for the circulatory system. Therefore, if the heart becomes weak, as may occur from a result of many different conditions, the circulatory system is affected. System malfunction can occur and the mechanism breaks down. The primary example of such a breakdown is heart failure. Acute failure, or a sudden decrease in cardiac output, can be caused by a number of things, such as anesthetics, exogenous drugs, arrhythmias, or coronary occlusion.

Abrupt failure of the heart to provide adequate blood flow leads to unconsciousness and death. Another example of heart failure is chronic failure. In this case, the heart has been damaged so that its ability to pump blood fails slowly over time. As the failure progresses, the venous pressure becomes too high and the individual can no longer compensate. The individual develops signs of decompensation. The dilated heart works at a mechanical disadvantage and chest pain may signal myocardial ischemia. Signs of congestion in the pulmonary system and the systemic system may appear as shortness of breath and a distended liver. At this point the increased venous pressure may no longer be improving cardic output but actually be damaging the heart. Once the heart is damaged the pump will not function as normal. A very obvious sign of circulation disturbance is a decrease in the skin temperature and a change in skin color resulting from insufficient blood flow.

In addition, heart failure causes changes in respirations. Slowing of the circulation can then lead to the development of a more rapid Cheyne-Stokes respirations. The most common cause of Cheyne-Stokes breathing is a decrease of the circulation time between the lungs and brain. Cheyne-Stokes breathing is initiated by a more rapid and deeper than normal respiration and rate. This in turn causes a decrease in $PCO_2$ in the pulmonary blood. Later, (depending on circulation time) the pulmonary blood reaches the brain, and the decreased $PCO_2$ affects the brain respiratory control center, and respiration is stimulated again leading to another cycle. In order for the Cheyne-Stokes oscillation to occur, sufficient time must elapse during the hyperpneic phase for the body fluid $PCO_2$ to fall considerably below the mean. This decrease in $PCO_2$ initiates the apneic phase which must last long enough for tissue $PCO_2$ to rise high above the mean. During hyperpneic phases, increased load on the heart (due to lowered blood pressure and increased ventricular filling) may cause cardiac failure. During apneic phases the inability of chemoreceptors (in aortic arch, carotid body but most responsive to $PCO_2$ in medulla) to initiate respiration due to respiratory center asphyxia may lead to respiratory failure.

b. Central Nervous System

An additional physiologic consideration directly influencing dying and death is the functioning, or malfunctioning, of the brain. Hemorrhage or growing brain tumors may interfere with other bodily functions, depending upon which structures in the brain are affected. For example, the brain contains the temperature regulating center. If this center is affected, uncontrollable fever may occur because the temperature sensing regulation center itself is malfunctioning. This interrelationship is further exemplified by the existence of brain tumors which may result in bleeding, potentially influencing malfunctioning of any system of the body. The more one understands normal physiology, especially the ability of the brain to control various functions throughout the body, the better able one is to understand the sequence of events occurring during the process of dying. The body, as a finely tuned instrument, contains a complicated communication network. As the dying process occurs the network may break down.

Within the brain are centers primarily concerned with promoting and regulating adequate oxygen/carbon dioxide exchange in all tissues, while maintaining vascular tone of blood vessels. Thus, the capacity of the circulatory system is never larger than the blood volume within it, which continually stimulates a regular effective heartbeat to pump blood. Since the brain and spinal cord are encased in rigid bony structures (skull and vertebrae), with essentially no capacity to expand, it is obvious that any swelling, bleeding, or tumor, within the central nervous system (CNS) would seriously affect function. Therefore, increased cerebrospinal fluid pressure is usually a manifestation of brain or spinal cord swelling. Causes of changes in CNS function include the following:

a) Infection of the lining of the brain caused by invading organisms. This situation seriously disrupts normal brain functioning due to the inflammatory swelling response.

b) Blood vessel disruption. In this situation the continuity of blood flow to various portions of the brain is interrupted by traveling clots of blood or tumor. Interruption of normal blood flow may also be caused by clotting of blood in vessels whose walls have been damaged, by congenital vascular malformation that bursts, or by blunt trauma to the skull itself. Bleeding beneath the cranium, by space occupation and increased pressure, may seriously damage brain function. Cerebrovascular episodes (CVE's), or strokes as they are also called, are included as one of three main causes of death. Only when major vessels within the brain are occluded is the vascular supply to the brain insufficiently impaired to cause death. Thus, in reality, the first stroke rarely kills; more often a series of ministrokes lead to a person's death.

c) Malignant tumors. Within the brain most tumors, whether slow or fast growing, are destructive due to their direct infringement on brain function as well as their occupation of space in the brain. Cancers, e.g., lung, colon, breast, etc., can spread to the brain (metastasis). In contrast, primary brain tumors themselves rarely spread outside the skull.

d) Metabolic changes. Metabolic changes can seriously effect normal brain function by interfering with integration of such activities as general body function or activities dependent upon the brain's vital centers. Disorders of acid-base balance, such as kidney failure, liver failure, or pancreatic failure represent one example of destruction of brain function. Insufficient hormone secretion by the thyroid, adrenal, or pituitary gland also influences brain function through biofeedback mechanisms mainly through the hypothalamus. In addition, an overdose of barbiturates, tranquilizers, or other medications may markedly depress cerebral functions leading to decompensation. Classic signs of brain decompensation indicating changes in consciousness include confusion, or inability to orient as to where you are, who you are, who your familiar loved ones are, or about the time of day, month, season, or year. More serious decompensation includes lethargy, a state of apathy with reduced ability to perform simple cognitive functions such as arithmetic; attention can only be stimulated or gained by tactile, auditory, or visual stimuli. Later, a state of sleep prevails and in stupor there can be withdrawal, or purposeless movement in response to touch, sound, or other stimuli, but no arousal or wakefulness occurs. In semicoma, movement can be elicited only in response to deep pain, while with coma, the last stage of consciousness, no communication is possible at all.

In the early stages of central nervous system decompensation, the pupils, which normally quickly constrict with exposure to light, become sluggish. When one side of the brain is compressed more than the other side, the corresponding pupillary light reaction may become more sluggish, but eventually both pupils lose their reactivity to light and dilate into a fixed position. Opiates, like morphine or heroin, can produce pinpoint pupillary constrictions. If severe brain depression occurs, and/or barbiturate overdose occurs, fixation of the pupils at about midpoint (that is halfway between maximal constriction and dilation) may be noted. As brain hypoxia becomes worse, the pupils become dilated.

Assessment of adequate cerebral blood flow can be made by determining the following behavioral characteristics: a) disorientation to place, time and event; b) anxiousness as evidenced by tone and pitch of voice, inappropriate laughter, picking at bed clothes, darting of eyes from one object to another; c) stupor, i.e., slow responses in speech and manner; unusual stimuli are needed to arouse patient. The preferred energy substrate the brain utilizes is glucose. If blood glucose levels drop below normal values and a patient becomes hypoglycemic, the body is capable for a time of conserving glucose for central nervous system utilization; however, when glucose levels drop below a certain point, the brain eventually will begin to use ketoacids as its energy source. Seizures will ultimately occur.

### c. Respiratory System

Simply stated, pulmonary failure is the inability of the pulmonary system to adequately supply oxygen and remove carbon dioxide from the bloodstream. In mild pulmonary failure, inadequate oxygen supply is observed first. Only much later does excretion of carbon dioxide become a problem; then carbon dioxide accumulates in the blood in the advanced stages of conditions resulting in pulmonary failure. Interestingly, the early symptoms and signs of inadequate oxygenation of the brain (hypoxia) or decreased carbon dioxide removal (hypercarbia) are rather similar. These signs and symptoms are confusion, hyperexcitability, irritability and a sense of fear ranging from mild anxiety all the way to a feeling of impending doom. In the beginning of prolong failure, shortness of breath occurs, with heavy exertion, as an increased breathing rate and depth. As the process continues, shortness of breath occurs with even less exercise until finally it may occur at rest. The four major causes of pulmonary failure are: interruption of pulmonary vascular supply (pulmonary thromboembolism), emphysema, alteration of the chest wall and CNS alterations. The lungs act as a remarkably good filter, preventing all particles traveling in the blood stream larger than red and white blood cells from reaching the systemic circulation. This sieve-like function is very useful for straining out abnormal intravascular material. In some situations, however, large blood clots from venous thrombi in the legs or thighs cause death. Pulmonary thromboembolism is the third most common mechanism of death.

In emphysema, large numbers of alveolar air sacs are destroyed so that the net surface area for air-blood exchange of gases is gradually but progressively reduced. Other examples that cause impaired gas exchange include pneumonias. These are caused by viral, bacterial, or fungal agents, all of which have, in common, a significant inflammatory reaction impeding oxygen transfer. The chest wall, or diaphragm, can be altered effectively to disturb its bellows' action of moving air in and out of the lungs. An example of this kind of problem includes fluid or air accumulation within the pleural space, which by filling up the space prevents the lung from expanding fully. Fluid accumulation in the pleural space can occur from congestive heart failure, infection or cancer metastasis. Another cause of mechanical alteration in the chest wall are those situations where deformity of the ribs or spine occurs, or, from muscle weakness as in multiple sclerosis. CNS alterations can offset rhythmical breathing patterns. In essence, depression of the respiratory centers in the lower medullary portion of the brain can lead to all the characteristics of pulmonary failure and ultimately to death.

### C. Physiological Changes Following Death

Body cooling occurs in the early hours following death which provides some information approximating the time of death. Based on an initial rectal or liver temperature of 98.6° Fahrenheit, the temperature falls about 1.5 degrees per hour in most bodies exposed to moderate ambient temperature. The rate of fall depends not only on environmental temperatures, but also is influenced by relative humidity and the insulating ability of clothing. During heat stroke the initial body temperature may be 5 to 10 degrees warmer than normal, making calculations much less reliable. In addition to alteration of body temperature, other body changes also occur following death. Immediately prior to death, during failure of the brain, lungs, or heart, the process of rigor mortis begins while, immediately following death, the processes of decomposition and liver mortis begin.

During rigor mortis the muscles of the body gradually become hardened due to lack of ATP needed for contracting to take place and accumulation of lactic acid and other products of anaerobic metabolism within muscle fibrils. The process begins within 2 to 4 hours of death but may be hastened by high fever, convulsions, or extreme muscle activity in the immediate pre-mortem period. In contrast, the onset of rigidity may be delayed for hours by rapid cooling in a chilly environment or by refrigeration. Rigor mortis sometimes is absent or much attenuated in the very old or young or in those severely debilitated with paucity of muscle tissue. Because shorter muscle fibers develop rigidity sooner than longer extremity muscle fibers, it is commonly stated that rigor mortis starts in the face and neck before spreading over the body. The persistence of rigidity is also directly influenced by body temperature, which in turn may be a function of surrounding temperature. Rigor mortis may disappear within 9 to 12 hours if the body is in an extremely hot environment and if decomposition begins early following a generalized bacterial infection or septicemia.

As bacteria spread throughout the body's blood vessels and gas (e.g., $CH_4$, $H_2S$, $CO_2$) is released within the tissues, the body becomes distended, with skin color changing from green to purple and black. This discoloration of the skin is caused by gravitational settling of blood cell hemoglobin into dilated capillaries. The color change often occurs in dependent positions of the body and is called "liver mortis." Liver mortis is usually absent where skin has borne the body's weight preventing the surface capillaries from receiving the deoxygenated hemoglobin. A halo of liver mortis can often be seen around these pressure points, revealing the exact body position during the death process. In severe hemorrhage or anemia, liver mortis may be so pale as to be inapparent. Formation of liver mortis begins from the moment blood circulation stops, usually perceptible within 2 hours post-mortem, and reaches a maximum between 8 to 12 hours after death.

The process of decomposition leading to decay and bacterial decomposition of the body, is subject to time variation, depending upon circumstances of death, environmental temperature and pre-existing body conditions. Autolysis refers to the action of digestive enzymes in the body, breaking down complex proteins, carbohydrates, and fats into simpler molecules. Gastrointestinal tract enzymes may cause autolysis and result in post-mortem rupture of the stomach or bowel wall. The large bowel is normally colonized with quantities of bacteria that, following death, aid in digestion of abdominal contents, reducing the tissues to a fluid consistency, and producing large amounts of foul-smelling gas. Sometimes discharge of fluid and gas occurs through body orifices (e.g., anus and vagina).

## SECTION B
## SYMPTOMS AND SYMPTOMATIC CARE

### I. SIGNS AND SYMPTOMS PRECEDING DEATH

Family understanding of what is happening should be assessed. Knowledge of what might happen should be shared with the family.

### Eating and Drinking

Fluid intake is most important, and the family should be made aware of this. Liquids that provide some nutrition may be suggested, but basically whatever the patient wants is what they are most likely to eat. Eating with the family is suggested for as long as possible.

1. Changes in appetite and taste - A patient may have a reduced appetite as a result of treatment (i.e., radiation and/or chemotherapy) or from the disease, itself. Anorexia may be influenced by the development of abnormalities of taste sensation. One study has demonstrated an elevated threshhold for sweet taste and a lowered threshhold for bitter taste. Therefore, food seems to lose its taste, and meat, in particular, tastes bad or lacks taste altogether. Zinc levels in the body may be depleted which decreases taste acuity.

Suggestions: Diet - A high caloric, high protein diet is most beneficial with a desired outcome of weight gain, positive nitrogen balance and a feeling of well being. This is difficult to achieve with dying patients and goals may have to be modified to include maintaining fluid balance and providing foods which will:

- be acceptable to the patient inducing him/her to eat
- provide essential calories and protein, vitamins and minerals
- be able to be swallowed and to be absorbed

Eating habits - Essentially the patient may eat whenever he/she wishes. Foods may be sweetened or flavored with extracts such as vanilla, lemon, etc., to make them more palatable. Eggs or cheese may be substituted for meats, or it may be determined that some meats are more acceptable than others, e.g., chicken or fish. Cold foods are more acceptable with mouth sores, so popsicles or slushes may be used as supplements. Rest before meals and small meals will be helpful to those patients who have become lethargic. Eating with the family, when possible, is recommended. Pain will need to be controlled if the patient is going to be able to eat with any satisfaction.

Diet supplements - High protein nutritional supplements may be used to augment whatever the patient is taking as his daily intake. "Ensure" in fruit flavors and "Susta-Cal" in chocolate are very acceptable. All these normally taste better cold although some individuals do not like cold foods and will accept foods at room temperature. (Note: family members should be reminded not to leave mild base supplement unrefrigerated for long periods of time.) Raw egg may be added daily to the supplements to increase protein intake. It should be mixed in very well. Blenderized yogurt can be used as well as non-fat dry milk added to whole milk, milk shakes or egg nogs. Instant breakfast preparations provide good nutritional supplement and are less expensive than some other preparations.

2. Nausea - Nausea and vomiting may be a consequence of the malignancy per se (mechanism not understood) or develop as a side effect of treatment. Obstruction due to tumor may be the cause and can usually only be corrected by treating the tumor or with surgery.

Vomiting may be associated with the following intra-abdominal conditions: acute gastritis; irritation of the peritoneum or mesentery. Vomiting may appear early in the course of peritonitis; obstruction of the viscera may produce smooth muscle spasm. It is important to note the time relationship between the onset of pain and the exact time of vomiting. With a sudden, severe peritoneal irritation, vomiting occurs early in the course of the disease and is likely to be violent.

Suggestion: Antiemetics such as one of the phenothiazenes can be used. They can be given orally (if not actively vomiting) or rectally. Higher doses than those usually recommended may be needed for rectal use. Frequently even these medications may be of little help. Small meals, or giving foods the patient requests, may help.

3. Bowel obstruction - Low small bowel obstruction may be associated with delayed vomiting, while vomiting occurs promptly with high small bowel lesions. With large bowel obstruction, vomiting may be a very late feature or may not occur at all. Massive intraperitoneal hemorrhage may occur in absence of vomiting and intussusception may be deceptive because vomiting may occur late or not at all. The physical characteristics of the vomitus should be noted. In acute gastritis the vomitus consists largely of gastric contents occasionally flecked with small amounts of blood. With intestinal obstruction the characteristics of the vomitus show considerable variation. As the condition progresses the character changes from gastric contents to bilious material, becoming yellowish green and, finally, consisting of brown, feculant-smelling fluid.

Suggestion: A nasal-gastric tube and suctioning may be of help although some individuals prefer no tube, yet want to drink liquids and vomit rather than use the tube or not drink.

4. Incontinence - Careful observation will aid in identifying the type of incontinence and lead to the appropriate treatment. Stress incontinence, or the involuntary loss of urine caused by straining, coughing, or lifting, may occur. Urge incontinence is the involuntary loss of urine caused by the sudden urge to void. It may occur with inflammatory disease of the bladder and urethra, but also with a neurogenic bladder with uninhibited contractions. Dribbling incontinence is the constant loss of urine in various amounts with or without stress. It may be produced by a fistula when the sphincters of the bladder have been damaged. Paradoxical incontinence, the involuntary dribbling of urine, is due to chronic urinary retention. This may be produced either by obstruction of the urethra in the male, as in benign prostatic hypertrophy, or secondarily to neurogenic bladder.

Suggestion: While medication can help take care of the problem; there may be occasion when a Foley Catheter will be more comfortable for all.

5. Constipation - Patients who are inactive, and frequently have intake of foods that lack roughage, bulk or fluid, may become constipated. Vincristine (a cancer chemotherapy drug) causes constipation as do the opiates (such as morphine) and other analgesics.

Suggestion: Caregivers should be requested to keep a record of the patient's bowel movements. Because of limited food intake, a bowel movement every 2-3 days may be acceptable. Increasing fluid intake, plus bulk in the diet and physical activity or position changes, will aid in preventing constipation. Bran and prunes are helpful additions in the diet. Stool softeners, such as Colace or Dulcolax, can be given orally or glycerine suppositories inserted to mechanically promote defecation. Oil retention or phosphate enemas may be used if nothing else helps, but only in consultation with the physician and with extreme care, or not at all, as rectal bleeding may result. Usually, regular use of laxatives is necessary to avoid constipation from the pain medication.

6. Weight loss - Cachexia is a frequent problem with patients with cancer, especially those who have solid tumors. The wasting of body tissues is in part due to metabolic starvation, but toxic tumor byproducts may also cause tissue wasting.

## Effects On the Body Of a Rapidly Growing Malignancy - Metabolic Starvation

One of the most important effects of a malignancy is the competition for metabolic substrates by the growing cancerous cells. Leukemic tissues, for instance, reproduce new cells so rapidly that tremendous demands are made on the body fluids for foodstuff, especially amino acids and vitamins. Thus while those tissues grow, other tissues are in various stages of malnutrition or starvation. A continued state of metabolic starvation is sufficient to cause death. Tissues preferentially use carbohydrates for energy but the carbohydrate storage capacity of the body is minimal--only a few hundred grams, which is only enough to supply the body with energy for body functions for about half a day. Thus, except for the first few hours of starvation, the major effects that occur are increasing depletion of fat and body protein. The symptom complex seen is the result of weight loss, decrease in body fat, protein and carbohydrate and the increased metabolic rate. The patient appears weak and tired and shows weight loss. The cause is complex leading to cachexia because of anorexia, nausea, vomiting or a gastrointestinal obstruction, compounded by loss of body fluids in association with bleeding or malignant growth. Intestinal absorption may be involved and the tumor, itself, may play a major part in its increased deman for essential nutrients or the cancer may release products that also affect the metabolic changes. Malabsorption that can occur can be a consequence of treatment or the disease. Certainly malabsorption has serious consequences to the patient. The patient may have difficulty absorbing essential nutrients, especially vitamins, producing vitamin deficiency and resulting in lesions of the mucous membranes making it more difficult to eat.

## Fat, Protein and Glucose Depletion Rate

Since fat is a prime source of energy, its depletion rate is relatively fast. Protein undergoes three different rates of depletion. Initially, breakdown of protein is rapid as protein is converted to glucose in the liver and kidney via gluconeogenesis. Glucose formed in this manner is used mainly to supply an uninterrupted source of energy substrate to the brain. After essential body protein, e.g., albumin, has been partially used during the early phase of starvation, the remaining body proteins are not so easily removed from the tissues. The rate of gluconeogenesis decreases to 1/3 to 1/5 of its previous rate and fat stores are used up more rapidly after most of the available gluconeogenic precursors have been depleted. However, once fat stores have been depleted, protein breakdown returns to its previous fast rate. Since proteins are absolutely necessary for the maintenance of cellular function, death ordinarily ensues when the body proteins have been depleted by 1/2 the normal level. Also since many vitamins are deficient in the tissue environment during starvation, metabolism is further inhibited through lack of activation of catalyzing agents (enzymes) with their essential vitamin coenzymes (e.g. Vitamin B components).

## Slow Heart Rate

An outstanding constant pecularity of starvation is sinus bradycardia which is not primarily due to nervous stimulation but instead due to lack of sufficient energy sources. Slow heart rate may also be a response to reduced circulatory demand due to reduced metabolism. This reduced metabolism is in part due to a decreased concentration of available metabolic substrate but also to changes in thyroxine, the primary metabolic rate regulating hormone.

There are two known pathways for metabolizing thyroxine in humans: one path is degradation to a compound which increases metabolism more than thyroxine, the other pathway is degradation into a substance that is metabolically inactive. It has been shown that during starvation thyroxine is preferentially converted to the inactive compound thus decreasing metabolic rate.

## Reduced Metabolic Rate

As metabolic rate gradually decreases during starvation, heart rate reaches a minimum when body weight loss reaches about 15 percent. Decreases in heart rate are accompanied by decrease in venous blood pressure and decreases in cardiac output along with prolonged systole. Mild cyanosis, cold skin, and increased circulatory times are also results of decreased cardiac output. As respiratory muscles are deprived of energy sources, they become weaker. With loss of strength of respiratory muscles, decreased vital capacity, decreased rate of respiration, respiratory insufficiency lead to poor oxygenation or arterial blood. The respiratory rate continually decreases during starvation until respiratory failure develops or Cheyne-Stokes breathing becomes apparent.

## Decreased Energy

As malignant cells continue to multiply, lack of normal cells or preferential increases in leukemic cells often leads to anemia and then to a chronic hypoxic state which also deprives the body of energy sources. Treatment effects can also lead to anemia. Under normal conditions when oxygen supply is adequate, 38 high energy molecules ATP, can be formed from each mole of glucose metabolized; without oxygen only 8 ATP can be formed using the same substrate. Thus even with normal amounts of carbohydrates available for metabolism, less than 25 percent of the normal amount of energy is available to cells under reduced oxygen tension.

## Effects on Respiration

In advancing disease, as hypoxia becomes more and more severe, the centers of the brainstem regulating the respiratory mechanism may lose their functional capacity and death will ensue due to respiratory failure. Under less severe circumstances reduction of arterial oxygen tension causes a vasodilation of the cerebrovascular system with a resultant increase in cerebral blood flow. Reduced $PO_2$ tension stimulates the respiratory centers to increase ventilation and increase blow-off of $CO_2$ leading to hypocapnia which has the opposite effect of increasing vascular resistance, lowering cerebral blood flow and sometimes leading to unconsciousness. In the liver and muscle, carbohydrates are broken down anaerobically creating an increase in blood lactic acid concentration and a corresponding acidosis. Most of the useful respiratory responses to hypoxia originate from chemoreceptors in the carotid and aortic bodies which are stimulated by an oxygen supply below their cellular needs due to a low arterial $PO_2$ or decreases in blood flow.

## Effect on Circulation

As hypoxia increases, tissue vessels continue to dilate allowing further increases in venous return and increasing cardiac output. This increased load on the heart may lead to cardiac failure.

If the total number of cells in the blood stream is increased due to leukemia there will also be an increase in blood volume which leads to an increase in circulation time. Blood circulating in body parts provides warmth. Blood carrying oxygen and nutrients travels from the heart to various body parts by way of arteries. Anything which obstructs an arterial vessel limits the blood supply to the part. Oxygen and nutrients are essential for cellular activity and the health of the tissue. Coldness of a body part may be explained by obstruction of a blood vessel. A factor in leukemia which may account for obstruction of a blood vessel is an aggregation of white blood cells. The aggregated cells could be carried along in the circulation and the previously plugged vessel could again provide blood to the part. Cyanosis is another symptom of inadequate circulation. Prolonged deprivation of the blood supply could result in tissue damage and necrosis. When the cardiac muscle is weakened the effectiveness of the cardiac pump is reduced resulting in decreased tissue perfusion. When cardiac output is decreased, blood flow is directed toward the heart and brain and diverted from other tissues and organs. One sees the signs of decreased perfusion, e.g., colder extremities, decreased urinary output and further deterioration in blood pressure as well as in neurological status. Inadequate supplies of oxygen to tissues can be reflected as impaired function (such as hyperexcitability followed by hypoactivity of irritable tissues), cyanosis, and acid-base abnormalities leading to acidosis.

7. Anemia - Most patients with cancer will have problems with anemia but causes may differ. Causes may be blood loss, hemolysis, non-hemolytic shortening of red cell survival plus decreased red cell production.

Pallor, ease of fatigue, weakness, lassitude, shortness of breath on exertion, faintness, and vertigo are the important general symptoms of anemia of whatever cause. These symptoms are due chiefly to increased circulatory effort, in part to insufficient oxygenation of the tissues, especially the brain. Usually symptoms of anemia do not become noticeable until the hemoglobin is lowered to half its normal value, unless there is coincidental fall in blood volume, as in shock or hemorrhage. Leukemias and lymphomas commonly give rise to anemia and thrombocytopenia. In turn, epistaxis, gum bleeding, petechiae, purpura, or frank hemorrhage may occur anywhere in the body. Systemic symptoms include weight loss, fatigue, heat intolerance, night sweats, fever, and pruritus.

Suggestion: A diet high in iron and proteins is suggested but will probably not correct the difficulty as it is rarely nutrition-related. Fatigue accompanying the anemia requires small meals and assistance in eating as desired/required by the patient. Foods difficult to chew are usually not acceptable.

8. Bleeding - Although this is one of the most feared complications, overt hemorrhage has been rare in home care for the dying child experience. If bleeding does occur, it is important to keep calm. Ice pack or pressure should be applied. Gelfoam or topical thrombin may be tried. A good supply of Chux and tissues needs to be available and used supplies disposed of so that the patient doesn't see the accumulations of blood.

Because of bleeding tendencies in patients with leukemia, rectal temperatures, suctioning and administration of injections are done very carefully, if at all.

Caregivers need to be reassured that there is nothing more that could be done for the patient in the hospital; however, if the bleeding distresses the family and/or patient, they may wish to return the patient to the hospital. Transfusions may be given for comfort in the local hospital emergency room if desired by the family and patient and ordered by their physician.

9. Cyanosis - The term "cyanosis" means blueness of the skin, and its cause is excessive amounts of deoxygenated hemoglobin which has an intensive dark blue color that is transmitted through the skin.

Quantity of Hemoglobin

One of the most important factors determining the degree of cyanosis is the quantity of deoxygenated hemoglobin in the arterial blood. It is not the percentage deoxygenation of the hemoglobin that causes the bluish hue of the skin, but principally the concentration of deoxygenated blood. In general, definite cyanosis appears whenever the arterial blood contains more than five grams percent of deoxygenated hemoglobin.

Rate of Blood Flow

Another important factor that affects the degree of cyanosis is the rate of blood flow through the skin, because this determines the amount of deoxygenation that occurs as the blood passes through the capillaries. Ordinarily, the metabolism of the skin is relatively low so that little deoxygenation occurs as the blood passes through the skin capillaries. If the blood flow becomes extremely sluggish, however, even a low metabolism can cause marked desaturation of the blood and, therefore, can cause cyanosis. This explains the cyanosis that appears in very cold weather, particularly in children or elderly who have thin skins.

Skin Thickness

A final factor that affects the blueness of the skin is skin thickness. For instance, in newborn babies, who have very thin skin, cyanosis occurs readily, particularly in highly vascular portions of the body, such as the heels. Also, in an adult, the lips and fingernails often appear cyanotic before the remainder of the body shows any blueness. Cyanosis is a common sign before death because of the slowing of circulation and of the very thin skin of the elderly.

10. Dyspnea - Dyspnea, air hunger, means primarily a desire for air with mental anguish associated with the effort to ventilate enough to satisfy the air demand. The two major facotrs which often enter into the development of the sensation of dyspnea are:

- Abnormality of the respiratory gases in the body fluids, especially hypercapnia and, to a much less extent, hypoxia
- Amount of work that must be performed by the respiratory muscles to provide adequate ventilation

At times, the levels of both carbon dioxide and oxygen in the body fluids are completely normal but to attain these the person has to breathe forcefully. In these instances the forceful activity of the respiratory muscles, themselves, gives the person a sensation of air hunger. In order to correctly assess the patient's physiological state relative to vital signs, the nurse should know the patient's normal values. Utilizing these data, the nurse should then make a judgment based on knowledge of normal value ranges of vital signs as to whether or not the patient's present measurements of heart rate, respiratory rate, and blood pressure indicate a stabilized state: a hypotensive state approaching shock, a hypertensive state, or a state requiring pain medication.

11. Respiratory distress - Caregivers should be aware of possible changes in respirations. It may be suggested that if and when respirations become irregular and/or labored, it is important that it is best to remain calm. The caregivers may wish to contact the nurse. Placing the patient in a semi-Fowler's position, or supporting the patient in an upright (sitting) position, may help alleviate distress. Suggestions to aid respiration include:

- Administering oxygen, using a Venturi mask or nasal prongs (depends on physician - may well be of limited use only in terminal stage)
- Suctioning, if necessary, to keep airway clear and prevent aspiration. If there is a tendency for bleeding, suctioning should be done very gently. This is usually done only if there is evidence of choking

- Increasing humidity
- Remove excess clothing

12. Seizures - Although the possibility of seizures is often feared by the patient's family, this, too, is rare. Family members can be taught to observe for signs of seizures and learn the precautions. If the caregiver observes and reports early seizure activity, such as jerky, incoordinate movements, the physician may order phenobarbital or another anticonvulsive to reduce the possibility of major seizure activity.

If the patient has a seizure, the caregiver may turn the patient's head to the side and protect the patient from falling or being injured by hitting something that may be hard or sharp. Incontinence and a brief loss of consciousness is normal. Following a seizure, drowsiness is common. Important to keep the oral cavity clean.

A balance between seizure control and awareness, which is acceptable to the family, needs to be maintained. The family may prefer slight seizure activity over a heavily sedated patient.

13. Skin - The skin is directly visible, palpable, and color is readily apparent. During dying one must be alert to color and temperature changes as well as to the presence of itching and signs of bleeding problems. Pallor and coldness of the skin may be present in patients with chronic anemia. The nail beds and conjunctiva are helpful in the estimation of the significance of pallor. Cyanosis may be present. Icterus (jaundice) may be a sign of rapid hemolysis of blood cells.

Purpura may be due to a number of deficiencies of the hemostatic mechanism. Purpuric lesions are classified either as petechiae or ecchymoses. Petechiae are small, superficial, cutaneous, or mucosal hemorrhages, less than 5mm in size. Ecchymoses are larger (greater than 5mm); they are purplish in color and have irregular borders. The common bruise is an ecchymosis.

Pruritis (with certain lymphomas) may be intense, resulting in extensive excoriation of the skin. There may be primary invasion of the skin by lymphoma or leukemia, and almost any type of secondary dermatitis may develop with these two disorders.

Suggestion: Skin care - Bony prominences should be identified for the family and a demonstration should be given on when and how to rub. Lotions such as Alpha Keri are moisturizing; lotions with alcohol are not. Adequate fluid and nutritional intake along with frequent turning for patients who lie in one or two positions will decrease likeliness of skin breakdown. A flotation pad with foam mattress or air mattress (which can be rented or purchased) is helpful. Lamb's wool may be utilized. If skin breakdown does occur it is important for all to realize healing may not occur because of the advanced process. The physician should be consulted for recommendations.

14. Bone tenderness and bone pain commonly accompany disorders of the blood forming organs. Although the sternum is commonly tender to point pressure, tenderness may develop as a consequence of increased proliferation of blood cells as in the leukemias and hemolytic anemia. Localized bone tenderness may be due to localized invasion of bone by leukemia or other malignancies, multiple myeloma or Hodgkin's disease.

Rapidly enlarging lymph nodes of whatever cause, with acute distention of the capsule, vary from "sore" to very tender. Slowly enlarging nodes produce no symptoms until they are large enough to result in mechanical difficulties. Enlarged mediastinal and hilar lymph nodes can compress the trachea, causing respiratory difficulty with a dry "brassy" cough, progressive dyspnea, orthopnea, and cyanosis. In addition, obstruction to lymphatic and venous return can cause swelling of the face and neck. Enlarged retroperitoneal, periaortic and perifemoral nodes can cause ascites and edema of the lower extremities. By encroachment on the stomach and intestine, massive splenic enlargement leads to early satiety, constipation, and/or diarrhea.

15. Muscles make up a major portion of the body and are the structural units that give us functional ability. During dying the muscles involved in maintaining sphincter control may be lost and result in incontinence of urine and bowels.

Suggestion: Positioning - The need for positioning varies with the size and age of the patient, diagnosis, complications, and the patient's own preference. The caregiver should be alerted to the need to change position for the patient who cannot do so for himself. How often to make a change, and what position will be comfortable and safe, should be included in the instructions and demonstration.

The patient and the family can determine where care will be given, whether in a bed in the bedroom on a couch or elsewhere. The patient may prefer to be in the living room or family room near the family activities. This has the advantage of keeping the patient involved with family life, but it may limit social activities for the family. A hospital bed may be helpful for the one who requires total care. The bed may be placed anywhere in the house that the family wishes. Whatever is used as a bed for the patient should be well protected with a plastic sheet or plastic mattress cover. Chux and ABD pads may be used to decrease laundry demands and facilitate care.

16. Mouth and Jaws - The oral cavity is the most accessible orifice and may reveal local diseases as well as signs of systemic disease. Few areas of the body are exposed to the degree of continuous insult to which the oral tissues are subjected. The constant exposure to mechanical, thermal, chemical, and microbiologic stress makes the tissue of the oral region a significant index of tissue tolerance and systemic defense. Therefore, systemic diseases that reduce tissue tolerance often have oral manifestation. In the dying process the oral cavity is damaged easily.

Suggestion: Mouth Care - Normal oral hygiene practices should be maintained and gentle brushing of teeth after eating encouraged. Topical anesthetics such as viscous xylocaine, 2 percent Cetacain Spray or Cepacol Lozenges with or without benzocaine may be used. To clean the mouth well, a 1:1 solution of normal saline plus hydrogen peroxide can be used to rinse or swab the mouth gently. Petroleum jelly on the lips is comforting if they are dry or rough and blistered. An oral pain medication may be needed with severe stomatitis. Elixir of benadryl, swished around the mouth and then swallowed, acts as a mild anesthetic as well as a mild antiemetic and sedative.

17. Effects of Renal Insufficiency on the Body Fluids - Uremia - The effect of acute renal shutdown, or of severe renal insufficiency on the body fluids, depends to a great extent on the water and food intake of the person after shutdown has occurred. The most important effects are:

- Generalized edema resulting from water retention
- Acidosis resulting from failure of the kidneys to rid the body of normal end products of metabolism
- High potassium concentration resulting from failure of potassium excretion
- High concentration of the nonprotein nitrogens, especially urea, resulting from failure of the body to excrete the metabolic end products

The condition is called uremia because of the high concentration of normal urinary excretory products that collect in the body fluids.

Uremic Coma

After a week or more of renal shutdown the sensorium of the patient becomes clouded, and he soon progresses into a state of coma. The acidosis is believed to be the principal factor responsible for the coma.

The respiration usually is deep and rapid in coma, which is a respiratory attempt to compensate for the metabolic acidosis. In addition to this, during the last day or so before death, the arterial pressure falls progressively, then rapidly in the last few hours. Death occurs usually when the pH of the blood falls to about 7.0.

18. Liver - The liver is a detoxifying system and with damage to the liver this function is impaired. Clotting factors are generated in the liver and without these factors hemorrhage will occur. The disease process leads to the development of hepatic failure, severe metabolic acidosis and acute cerebral edema. With the liver being affected there is widespread metabolic disturbance and loss of clotting factor. Hemorrhage in all systems may occur and extreme caution must be observed. When there is liver metastasis, which can get to be massive with advanced cancer, you get some specific symptoms of jaundice, itching, nausea, sometimes anorexia, and a significant fall in the serum albumin levels. You may end up with peripheral edema. The direct metabolism is affected. The synthesis of the components for blood coagulation may be affected and there may be increased danger of bleeding. Not only is the patient with the advanced malignant disease frequently

anemic but there can also be an increased tendency for bleeding and resulting coagulation problems. In this case it is desirable, if possible, to avoid intramuscular injections and to be alert to the potential for drug overdose. This would be particularly true for the patient with liver involvement. The excessive or inappropriate use of tranquilizers, the biochemical disturbances that can come from the disease itself, as well as acute vitamin deficiency, can all inhibit liver function.

19. Pneumonia - An acute inflammatory reaction takes place in the lungs and impairs the reserve capacity of the lungs themselves, with less reserve functional capacity available to transfer oxygen through the bloodstream to the other important body organ systems. This, in turn, impairs other organ systems' contribution to fight the infection. In an integrated system such as ours, each system has reserve capacity to help should another system begin to fail. In the example stated above, although the bloodstream may have to carry less oxygen per unit volume, increased heart action may increase the transit time or blood volume per unit time and make up for the oxygen deficiency. Moreover, preferential distribution of blood to important organs in the body considered vitally necessary for survival also occurs. By rallying several more vital organ systems, survival may be achieved for a short time.

20. Environmental Effects - The hospital environment is another factor which further increases the risk of infection for the patient with cancer. In the hospital there are increased numbers of organisms many of which are very virulent in nature. The greater the number and virulence of pathogens, the greater the chance of infection. Hospitalized patients are often exposed to various supportive measures--Foley Catheters, intravenous fluids, IPPB treatments--each of which contributes significantly as a portal of entry for infectious organisms. Always remember that a person dying is more prone and susceptible to infections and that one needs to be careful at all times.

## II. SUMMARY OF EVENTS PRECEDING DEATH

It is helpful to the caregiver to know as many possibilities of what might happen just prior to death. Reducing the number of unknowns will help keep the family calm. The expected manner of death is based on specific disease entity and complications. Physiological changes which usually occur and possible interventions or comfort measures which the caregivers can use are as follows:

1. Temperature - If the temperature of the body is high, the patient may feel very hot but appear to be comfortable. As the circulation decreases the heat regulation system may fail. With decreased circulation, the patient's extremities usually become cooler first as the time of death nears. There may be coldness, pallor and cyanosis and the color of the patient's face may become ashen and cyanotic. Some authorities feel that, no matter how cold the body surface is, the dying patient is usually not conscious of cold.

If the body surface becomes cool and covered with damp, cold perspiration, bath blankets help absorb the perspiration and aid in keeping the patient dry. Light, loose coverings should be used. Excessive cover may increase restlessness. Sometimes the patient may prefer almost nothing on.

2. Pulse - As the circulation decreases the pedal and radial pulses become imperceptible. The apical pulse may become very rapid and then slower, irregular and less audible.

3. Gastrointestinal Changes - Fluids such as water, tea, fruit juices (or ice chips to suck on) may be offered as long as the person desires to drink and can swallow. Avoid milk products because they tend to produce mucus. If the patient is too weak to drink from a cup or suck through a straw, small amounts of fluid can be given using a teaspoon, special feeder cup, syringe or finger over straw method. Stop giving fluids when the patient is unable to swallow.

Mouth care is especially important when the patient is no longer taking fluids or is mouth breathing. Vaseline or lubricant may be applied to dry lips.

If there is excessive oral secretion, turn the patient on the side to facilitate drainage. Use of a suction machine may help alleviate caregiver concerns. Suctioning is seldom needed, however, because the patient is usually able to handle his own secretions. Suctioning the patient, unless there is a real indication for it, may cause more discomfort than help.

Rattling respirations or gurgling in the back of the patient's throat may distress family members but don't appear to cause the patient discomfort.

As sphincters relax, involuntary defecation or urinary incontinence may occur. It is well to have Chux and ABD pads available.

4. Respirations - To facilitate breathing and comfort, the patient may be placed on his back or slightly turned on his side with his head slightly elevated and firmly supported on a pillow.

Usually labored respirations are relieved if the patient is propped in a well supported sitting position. Whatever position eases respirations is good. No matter what position the patient is in, however, he must be well supported to be comfortable.

Administering oxygen may be warranted in some instances to help the person who is experiencing air hunger - possibly helps relieve some anxiety.

Respirations may increase to 30-40 per minute and then become very irregular and shallow. There may be alternating periods of apnea and then a slowing from 40 to 30 to 20 to 6-4 to 3-2 respirations per minute.

5. Central Nervous System - Some patients are alert and mentally clear until the moment of death. Others may become confused, semiconscious or even unconscious for (several) hours. The interval between insensibility and death varies from seconds to hours to even several days. Consciousness is often retained longer than we think. Speech may become increasingly difficult to understand or incoherent and it may require a great amount of effort on the part of the patient. It is well to remind the caregiver and family member that hearing is the last sense to be lost. It is difficult to determine when hearing is completely lost. Talking should be in a natural tone of voice. Soothing music may be enjoyable for some families. Family members need to be encouraged to touch and talk with the patient even though the patient may not respond, and they should avoid speaking in the presence of the patient about subjects which may be upsetting to the patient.

6. Involuntary Movements - Caregivers should be prepared for the rare possibility of involuntary movements which occur in perhaps 1 out of 100 patients. These movements probably result from a variety of metabolic

end-processes such as uremia, liver failure or keto-acidosis. These have a stimulating effect on the central and peripheral nervous system. These may be caused by changes in electrolyte metabolism coupled with dehydration. The physician may wish to use IM Diazepan for control

7. Eyes - The eyes may become either sunken or protuberant and glazed. Eye secretions may be removed carefully with a warm damp cloth. The pupils may become fixed and dilated.

## General Considerations

A family member may ask "How much longer?" Usually the answer is, "No one knows." The nurse should listen quietly to family concerns, anxieties and ambivalent feelings. When the impending signs of death, such as extreme changes in the vital signs, cold extremities and cyanosis appear, the answer could be "not long."

How the family members deal with their dying member's perceptions and feelings is an individual matter.

The part that faith or religion play in helping families meet or face death must not be overlooked. The nurse must be conscious of these needs and have respect for the religious practices of family members.

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# MODULE VII A: PHARMACOLOGY

PARTICIPANT MANUAL

DEVELOPED BY:

Arthur Lipman, Pharm. D.

# MODULE VII A: PHARMACOLOGY

## Purpose and Goals

The purpose of Module VII A is to introduce the hospice care nurse to the types of symptoms commonly seen in the terminally ill cancer patient for which drug therapy is appropriate and to describe appropriate pharmacological intervention.

The goals of the module are to assist participants to:

- Identify drug induced undesirable effects
- Have appropriate input into planning drug therapy
- Understand the types and dimensions of pain seen in patients with advanced, irreversible cancer
- Select and recommend appropriate drug therapy and to suggest other therapeutic modalities for nausea, constipation, diarrhea, anorexia and other symptoms common in terminal disease
- Appreciate the need for high quality physical and psychosocial care for successful symptom management

## Module Content

The module content includes the following topic areas:

- Common symptoms in terminal disease
- Definitions of pain
- Dimensions of severe, chronic pain
- Presentation of severe, chronic pain
- Modalities of managing pain
- Affect and pain
- Analgesic agents
- Analgesic dosing
- Myths about narcotic analgesics
- Communications about symptoms and the disease process and pain
- Nausea and vomiting

- Diarrhea
- Constipation
- Iatrogenic symptoms
- Adjunctive steroid therapy
- Marijuana and LSD
- Life style and symptom control

Learning Objectives

At the conclusion of Module VII A, participants will be able to:

- List six common symptoms associated with advanced cancer and indicate which may have an iatrogenic component
- Define the major differences between acute and chronic pain
- Describe the aching to agony continuum of chronic pain
- List three dimensions of chronic pain
- Describe the presenting symptoms of severe, chronic pain
- Describe the reasons for selecting a relatively high narcotic dose in severe, chronic pain
- List equipotent doses and comparable durations of action of morphine, methadone and meperidine
- Describe the problem of drug accumulation associated with methadone dosed every 4 hours
- Describe the rationale for regularly scheduled narcotic doses rather than prn dosing in severe, chronic pain of a physical origin
- Define endorphins
- Describe the rationale of adjunctive phenothiazines in severe, chronic pain
- Describe two reasons why tricyclic antidepressants should not be routinely used in reactive depression associated with chronic pain
- List five etiologies of nausea in cancer patients

- List three reasons why piperazine side chain phenothiazines are the favored group in nausea associated with narcotics
- List the five major classes of cathartics and one advantage and disadvantage of each class
- List five symptoms for which steroids may be helpful in advanced cancer patients
- Describe the original rationale of adding cocaine to narcotic cocktails and the results of a double-blind study which mediates against the use of cocaine in this manner
- List three possible causes of diarrhea and constipation in advanced cancer patients
- Describe two potential advantages and disadvantages of using marijuana as an adjunctive drug in chemotherapy

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# THE PATIENT IN PAIN: NEW CONCEPTS

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Over the past few months we have been talking with a number of nurses who work in outpatient settings offering services to patients with cancer. In particular, we have asked them about the pain responses observed in and reported by the patients whom they encounter. We have been struck by the fact that more than one nurse is surprised that there is not more pain with cancer.

If most nurses carry the notion that pain is usual with cancer, then one must assume that many nurses believe that pain and cancer always go hand in hand (as does the public at large). In reality, this is not the case. In fact, medical practitioners who work in the field of oncology comment that this belief about pain is one of the mythologies about cancer. They do point out, however, that pain is a serious problem in certain types of cancer, and, in some cases, can be an extremely difficult problem in clinical management.

Commenting on pain in cancer, as described in British publications, Twycross notes that as many as 50% of all cancer patients have no pain or negligible discomfort, that 40% experience severe pain, and that the remainder have less intense pain.[1] He also notes, however, that the incidence of pain is higher in terminal cancer hospitals, but that the causes of pain in advanced malignant disease come from a variety of sources and not from malignancy per se.

The purpose of this paper is twofold: to examine the relationship between pain and cancer as reported in the current literature, and to identify some of the problems that interfere with effective clinical management of pain in patients with malignancies. The discussion has been organized under three general topics: variations in pain response and reactions, and the major circumstances which influence responses to pain; diagnosis and treatment of pain in cancer, and a comparison of medical and nursing approaches to the problem; and attitudes toward pain and habits of nursing practice.

## VARIATIONS IN PAIN RESPONSE AND REACTION

### Definition of Pain and Selected Research Findings

Pain has been defined as a response to noxious stimulation; an experience that is partly perception, partly reaction; a signal; a threat, a product of consciousness. No definition of pain, however, is ever completely satisfactory-perhaps not even to the person who proposes it. The problem is not that any one of the many definitions is wrong, but that each is somehow incomplete. Thinking of pain as

> ...an abstract concept which refers to (1) a personal, private sensation of hurt; (2) a harmful stimulus which signals current or impending tissue damage; (3) a pattern of responses which operates to protect the organism from harm

as suggested by Sternbach is particularly helpful in thinking about the management of pain in cancer.[2]

*...a personal, private sensation of hurt.* The part which the meaning of stimuli capable of producing pain has for the individual, the way the individual defines the situation he is in, and the part the individual's personal experiences play in determining the experience of pain are recognized but difficult to assess.

Anthropologists, missionaries, and others who observe people with cultural orientations different from their own have been sensitive to the fact that culture influences pain behavior. Precisely how such an influence is manifested clinically is easy to describe, however. Zborowsky, for example, while delineating patterns of behavior more commonly observed in people of one ethnic group than in another, stressed the point that within a given cultural group there are wide variations at either end of the continuum from the modal pattern; and that similar patterns of behavior might have very different meanings to individuals in different ethnic groups. Thus, while sensitivity to the existence of a culturally influenced pattern of pain behavior is important, validating the meaning of the behavior with the individual is critical.[3] The cultural values of a people influence not only the meaning which pain may have for them, but also the patterns of behavior used in dealing with the experience.

Culture also influences, to a large extent, what the individual thinks should be done about the pain. In some cultures, pain may be seen and accepted as a part of the human condition. In others, pain may be seen as part of the human condition, but not accepted as such. In the United States, we go to great lengths to avoid pain, control it, or eliminate it, for pain tends not to be accepted. This is not necessarily good or bad, right or wrong. The prevailing cultural belief system, however, does influence both what people do about pain and what they expect of those who would help them with pain.[4]

Because of the peculiar function which pain serves as a test of awareness and of the trust placed in pain to provide reassurance that what is perceived is true ("pinch me-I must be dreaming"), it is difficult to accept the fact that two individuals exposed to similar physical stimuli perceive the sensory data differently. Nevertheless, this appears to be true even when the anatomical structures that subserve pain are intact and functioning.

It is generally recognized that people vary in the accuracy with which they estimate magnitude. Petrie and others have demonstrated a relationship between judgment of size and response to pain. On the basis of her experiment, she identified three types:

> *augmenters:* subjects who consistently increase the magnitude of sensory data,
> *reducers:* subjects who consistently decrease the magnitude of sensory data, and
> *moderates:* subjects who neither increase nor decrease the magnitude of sensory data.

As might be expected, augmenters tolerate pain for shorter periods of time than reducers or moderates; and reducers tolerate pain longer than either augmenters or moderates.[5]

Experimental psychologists have found that individuals vary in the extent to which they depend on external stimulus characteristics in making perceptual judgments. Field-dependent subjects appear to be less responsive to noxious stimulation - at least experimentally - than are field-independent subjects. If such differences are borne out clinically, the environment may prove to be a very important factor in pain management for field-dependent patients.

Cognitive dissonance may also play a part in pain experience, according to experimental work by Zimbardo and others. Subjects in the group described as "high dissonance" tended to perceive noxious stimuli at a low intensity. The thesis of this experiment is that voluntary commitment to behavior dissonant with the value or motive of pain avoidance can reduce the effectiveness of that value or motive on behavior. The perception of the stimuli was altered as effectively as if the intensity of the stimuli were reduced.[6] Empirically, most of us have observed that an otherwise uncomfortable, or at least mildly uncomfortable, experience seems not to hurt as much if we have some choice about subjecting ourselves to the experience.

Undoubtedly, age and sex also influence pain - both what is experienced and the behavior associated with the experience. Since both age and sex are so closely related to socialization in a cultural group and expectations of others in the group, it is difficult to indicate with any degree of precision just what part they play in the pain experience.

*...a harmful stimulus which signals current or impending tissue damage.* One of the earliest bits of knowledge which we acquire about pain is that it signals harm or the threat of harm. The ability to experience pain is thus a very important protective device. Pain is unpleasant and it has an urgency about it which makes it difficult to ignore or to put aside.

This works very well in acute pain; however, in situations in which pain is long-term, and the stimuli cannot be removed, the patient is put in a bind. He is continuously alerted that something is wrong, that something harmful and dangerous to his life and integrity is present. His past experience tells him to run away or eliminate the source of the difficulty, but he may not be able to do either. This is both frustrating and anxiety-provoking.

Numerous studies have shown that anxiety is a significant factor in determining pain response. Anxiety not only intensifies the experience of pain, but it can be communicated effectively, thus affecting not only the behavior of the subject but also those in contact with him. It is regarded by many as the single most important factor influencing the response to noxious stimulation.[7]

Anxiety also appears to be a factor in determining differences in the ability of individuals to tolerate or endure pain. It is not nearly so difficult to endure pain when the maximum intensity, the length of time it might last, and a tolerable rate of known damage or harm can be predicted. Much of the anxiety related to pain among persons with cancer is related to the unknown and fear of the known in relation to these three factors.

*...a pattern of responses which operate to protect the organism from harm.* This pattern of responses which we call pain is a response of the whole organism to that which is harming it or is threatening harm. We cannot understand pain as a pattern of response in the individual with cancer unless we consider: 1) the physical basis of the stimuli, 2) the meaning of the stimuli to the individual, 3) the context of the situation in which the stimuli are encountered, and 4) past experiences with pain and the learning which has accompanied these experiences.

Pain cannot be understood simply as a physiological, a social, a psychological or an anthropological pattern, even though scientifically we try to understand it in each of these terms. For this reason it has been very difficult to equate the findings on pain experimentally produced in the laboratory with pathological pain. For many years, Howard K. Beecher has been in the vanguard of those who stress the importance of the meaning of the stimulus and the meaning of the situation in which the stimulus is experienced in order to determine the response referred to as pain.[8]

## Pain in Cancer - Site and Stage

Patients with a diagnosis of cancer may have pain arising from pathological changes directly related to the infiltration of nerves, blood vessels, or the lymphatic system by tumor cells; to mechanical pressure of the tumor (or metastases) on blood or lymph vessels; to invasion of periosteum or relatively inelastic connective tissues; or to inflammatory and necrotic tissue change in any pain sensitive area of the body.[9] Treatment directed toward removing, destroying or diminishing the tumor (such as irradiation, hormonal therapy, chemotherapy, or surgery) can be very effective in relieving this type of pain. In instances in which, either because of the site of the malignancy or the extensiveness of the neoplastic involvement, such treatment is contra-indicated or not practical, approaches directed to interrupting or altering the conduction of nerve impulses by neurosurgery, anesthetic blocks, electronic stimulation or some type of bio-feedback mechanism may be palliative.

Pain in patients with cancer may be secondary to the surgical intervention employed to treat the patient. Such surgery ranges from the relatively simple and limited to the very extensive and complex procedure. There is no consistent, direct relationship between size of wound and pain intensity. Postoperative pain is a variable among individuals with a malignancy as it is among individuals with other diagnoses. Again, anxiety is a significant variable. Pain accompanying such procedures may be acute, but it is ordinarily limited in time. Each person's need for narcotic analgesia must be considered on its own merits - that is, the need for analgesia is not automatically intense because the patient has a malignancy, nor, on the other hand, must narcotic analgesia be restricted for fear the patient might need it worse later. Pain can be successfully managed, but management requires careful assessment of the situation, confidence, and the patient's participation in the management.

Pain may also arise from pathological conditions which are secondary to the malignancy. Some of these are preventable. In this category, of particular significance are problems related to malnutrition. Depression, anorexia, nausea and vomiting, diarrhea, loss of fluid and electrolytes in body fluids or drainage - conditions which often accompany malignancy - pose serious threats to the person's nutritional status.[10] Changes in body metabolism as a result of the proliferating malignant tissue and inflammatory processes in adjacent sites put drains on limited nutritional input. As a result, patients become weak, debilitated, cachetic, and immobile physically, and increasingly depressed, worried, and fearful psychologically. Maintaining optimal nutrition is important to keeping the patient up, interested, alert to the world about him, and free from many of the secondary causes of pain and discomfort.

Regardless of the stage of the patient's illness, each complaint of pain deserves to be considered on its own merit. Because the patient is in a terminal phase, pain is not necessarily severe nor is it necessarily due to the malignancy. On the other hand, it may be severe; and, if it is, it is important to alleviate it.

## Pain in Cancer: Fears and Anxieties

Guilt frequently accompanies pain, and a surprising number of patients with cancer are plagued with feelings of guilt. As they search for some meaning in the catastrophe which has befallen them, unresolved feelings of ill will toward others, remorse for events of the past, or even feelings that they might have been negligent in seeking medical advice or in caring for their bodies aroused feelings. It is difficult to determine if they actually make the pain more intense, but they may make it more difficult for the patient to participate effectively in the management of pain, since he sees both the disease and the pain as punishment for a transgression. This may relate to a puzzling finding of Jacox and Stewart that, among some highly anxious patients with metastatic cancer, there seemed to be a tendency to deny the existence of pain.[11]

Bard reports that the most common fears expressed by patients with malignancies are: progressive deterioration of the body; painful death; and abandonment by others.[12] The last is a very real fear. The American family system places a great deal of responsibility on the nuclear family - the family of procreation. In a highly mobile modern society, it is essential that the family unit be quite self-sufficient and that its members become adept at using secondary systems of relationships to meet needs that the primary group is incapable of meeting. When family members are young and healthy, this type of system works fairly well. As people grow older or when major crises occur, the cushioning effect which a closely knit extended family is in a position to provide is simply not there; and families must look to various types of specialized services for assistance. This is very expensive and is apt to be impersonal. The expenses connected with the treatment and care of a family member with cancer may completely wreck the financial solvency of a family with even above average security, especially if it occurs in the years after fifty. Thus, the fear that the family will bankrupt itself in trying to provide care may be even greater than the fear that the family members will abandon the patient.

Dr. Cecily Saunders once remarked that one of the very important contributions of the care center (hospice) she directs is to provide patients with a sense of security, of knowing they will be cared for as long as they live. By providing the care which families are not able to give, they are freed from guilt feelings that accrue when they are unable to meet all of the needs of the patient themselves, hence they are freed to provide the support that only family members can supply to one another.

## THE ASSESSMENT AND MANAGEMENT OF PAIN

The assessment of pain, whether by a nurse or by a physician, has three main objectives: to understand what the patient is experiencing, to determine, if possible, the physical nature of the phenomenon which has precipitated this experience, and to evaluate the effect which the experience is having on the patient. The professional background of the person making the assessment determines to some extent which of these objectives is given the greatest emphasis.

In attempting to understand what the patient is experiencing, one seeks information which describes the location, intensity, and type of sensation. This is personal, private information which only the patient experiences, and the patient is the expert. Others can only infer or imagine what the experience is like. The main task is to facilitate the communication of what is being experienced.

Knowing the physical nature of the phenomenon helps one to determine the organic base for the noxious stimuli entering the central nervous system. Thus, medical science provides the base of expertise in this area. The patient is an important source of data: what makes the pain worse? does this hurt? show me with your finger; is it worse in the morning or evening? The physical examination, laboratory and X-ray work, consultations with various types of medical specialists are the tools by which the nature of the physical problem is identified and evaluated.

The third element in the assessment involves eliciting information which will provide insight into what the patient is doing with the information, data, or impulses which enter the nervous system. This part of the assessment is the most difficult and, in many respects, the most inexact because we do not know that we have all of the variables which may be involved; because the variables which we do know have the potential for influencing the processing do not function independently; and because while some of these variables can be measured with a fair amount of precision, others are more elusive.

In respect to this third element in assessment, the patient is the source of data. but the expertise of the professionals involved is necessary to the best interpretation of the data. There is no substitute for pooling information and clarifying relationships between bits of information that may have a bearing. In some situations, such group exchange may involve a variety of health professionals - physician, surgeon, radiologist, anesthesiologist, oncologist, nurse, social worker. In others, it may involve only a patient, a nurse, and a physician or just a patient and his physician. Each discipline has its own perspective, its own ways of accumulating data, and, as a consequence, different data as well as different insights accrue. This is true with any patient and particularly with patients who have pain of long duration.

There are two special problems that the patient terminally ill with cancer poses for practitioners. Because the patient has cancer, all pain may be thought of as a concomitant of the illness and the effort to determine the cause may be slighted; and because the patient has cancer, there is a notion that giving an analgesic is a good or kind thing to do: so, the patient is going, what difference if he becomes addicted, if he is drowsy and groggy; it's better than being aware of what is happening to him.

We believe that each complaint of the patient, regardless of his diagnosis or whether he is terminally ill, should be carefully assessed and treated. Many of the patient's pains are due to problems in tissues and systems which are not directly involved in the malignancy. Constipation, hemorrhoids, musculo-skeletal tension, pressure of bony prominances at points of weight bearing are some of the many physical origins of pain; but there are multiple sources and multiple kinds of pain in the terminal stages of cancer. A poignant episode was recounted recently by a nursing colleague:

> *...I had a group of students once who took as a small study a group of patients and asked them, 'tell me about your pain.' And one old gentleman said, 'it's very interesting that you would ask, because no one ever has.' And he said, 'what kind of pain are you interested in? Are you interested in the pain that is racking my body right now and from which I will never recover? Are you asking about the pain of my life when I lost my daughter? Are you talking about the pain of my loneliness because I have no one who care?'*[13]

## "Staying"

Lemon has observed that cancer pain is often most unbearable because hope, understanding, and personal interest have been withheld, consciously or unconsciously, from the patient by his physician or nursing attendants.[14]

"Staying," then, is an additional element in the management of pain: staying in the sense not so much of actual physical presence - though at times this is part of it - but staying in the sense of being open or available to the patient. For the nurse to stay confident that one is helping, that what one does is meaningful to ones' self as well as to the patient, that one is genuine, and real, and present when needed is essential.

This is not easy - it will involve a rethinking of many facets of the care and treatment. Not only is pain in another human being anxiety provoking: it is especially so to stay with a patient as the pain continues. Part of a well established tradition, only recently begun to be questioned, is the idea that somehow, somewhere in the education of the nurse and the physician, something magic happens to free them from personal reaction to pain, mutilation, disfigurement, offensive odors, sights or sounds, while at the same time preserving and, in fact, nurturing an exquisite sense of sensitivity and compassion. In fact, personal reactions to unrelieved pain, disfigurement, and mutilation are a real strain in providing care to such patients. Furthermore the patients whose pains are not completely relieved and the patients whose illnesses cannot be cured are, in some sense, an affront to care and treatment - a reminder of man's finiteness and limited capacity to control his environment.

To stay requires a deep conviction of the worth of what one is doing and an awareness of the help one can bring. The maintenance of such an approach is almost impossible in settings which are organized around cure as the prime goal. Providing person-centered care in such situations involves both recognition of the strains involved and a strong support system for the staff. The capacity for staying means being able to give with no guarantee of return. The patient who is in pain and the patient who is terminally ill are in a limited position to provide feedback that makes one feel good about what one is doing. The strong support system can help to make up for this.

## Confidence and Competence

In working with patients in pain who have a diagnosis of cancer, the circumstances which define the situation for the patient are of special significance. We have previously referred to the mythology which surrounds cancer and which, since both patients and the health professionals who work with them are products of their culture, influences the nature of the problem.

Uncertainty is a powerful stimulus to the generation of anxiety. While there is much uncertainty about pain in cancer, there is much that is certain, or at least reasonably certain. One source of considerable anxiety stems from the patient's fear that he will not be able to deal with the pain if it gets worse or if it continues indefinitely. Twycross, Lemon, Saunders, and others who have worked intensively with terminally ill cancer patients have suggested that intractable pain in such instances is infrequent, if not rare. However, simply telling the patient this is not apt to be convincing, unless one can demonstrate the ability to manage pain effectively here and now. Saunders has referred to the importance of being able to demonstrate that one can get on top of the pain by proper use of drugs and other measures.[15] Twycross refers to "quiet confidence" and "cautious optimism."[16] The patient needs to feel that those responsible for managing his pain are both competent and dependable.

Demonstrating effectiveness is important to being considered competent and dependable. However, few patients expect a 100% batting avarage. The patient's confidence in those treating or caring for him rests with the knowledge that his complaints are heard and attended to and that not all of his aches and pains will be attributed to the neoplastic process. Knowing that the patient has a terminal illness, like the knowing that a patient is aged, need not make all that is done for him seem fruitless and of no consequence.

## Patient Participation

Saunders has pointed out in her writings about physical distress in the dying patient that chronic pain is "a situation rather than an event, and the hardest aspect of the situation for the patient is that it seems to be meaningless as well as endless."[17] Her work with cancer patients and methods of relieving pain help us understand what is meant by the caring process. Clearly, an accurate assessment of the elements contributing to the patient's pain is essential, but it can result in very little unless it is followed by a regimen of treatment that makes effective use of drugs and other measures to help the patient find relief from his pain.

One important principle in pain management is to get over the fear-of-making-someone-an addict syndrome and be willing to utilize mild analgesics in a variety of combinations to assist the patient in finding comfort. In this area, we believe, Dr. Saunders has made a tremendous contribution to the control of pain in terminal cancer. There are several rather important principles that she follows: the drug selection and drug dosage is individualized for patients; drugs used for pain management are given in small doses at 4-6 hour intervals according to a regular schedule; the patient himself is involved in the process of deciding what drugs and dosage combinations work best for him.[18] This approach to control of pain releases the patient from having to bargain for drugs with the staff and, by allowing him opportunities to participate in decisions, he maintains some control over his final days of living.

Having used a similar approach in her work with terminal cancer patients, Col. Madelaine Bader of the Army Nurse Corps made the following observation:

> *This kind of pain control relieves the patient from becoming dependent upon clocks and persons administering the drugs. It permits him to complete his 'unfinished business' without being consumed by pain, or to engage in those pursuits which make his remaining time both satisfying, meaningful, and serene without the threat of pain.*

## Outcomes of Fragmentation

The modern-day treatment of cancer in the United States typically involves treatment by different types of highly specialized experts. The high degree of specialization permits the application of a high degree of scientific expertise to one aspect of the patient's problem. The specialist is maximally expert to the extent that he is free to concentrate on his field. The patient, however, is an integrated whole - his problems do not sort themselves out into neat, tidy packages; and his response to his care and treatment is that of a whole person. Therefore, there must be some one place or person where treatment of care considers the whole patient. Ideally, we believe that this would be some type of collegial, nurse-physician team.

Consider the situation of Ms. Riley. In the course of the two-year period from initial diagnosis until her death, she was either separately, successively, or concurrently under the care of an internist, two surgeons, two roentgenologists, and three oncologists. In addition, she was seen once in consultation by a dermatologist and once by a urologist. All ten of these specialists at one time or another prescribed one or more medications. When she developed urticaria at one point, the oncologist indicated it was not due to the drugs being used in chemotherapy, but gave no advice on any other drug. She was referred to the dermatologist who discontinued all medication and gave her a new medication. When the hives cleared up, the oncologist was most unhappy that she was not taking the drugs he had prescribed. The patient. naturally, concluded that no one knew or cared about anything except his little bit of treatment, and that somewhere she, as a person, had been lost in the shuffle. Unfortunately Ms. Riley's situation is all too common.

## ATTITUDES TOWARD PAIN

Thus far the discussion has been concerned with pain as experienced by people in variable ways and with special meanings associated with the word cancer. We have examined methods for the assessment and treatment of pain in cancer and have outlined some general principles basic to effective pain management. Notwithstanding the soundness of these principles underlying both medical and nursing practice, there is much to suggest that the actual management of pain in patients with cancer leaves much to be desired. On the one hand, the patient's basic pain problem may not be recognized, or he may be labeled as a "crock." On the other hand, he may be so "snowed under" with medication that he is cut off from effective social interaction.

In our judgment these extremes are not uncommon in American hospitals. Further it is possible that the attitudes of the people providing care may foster treatment practices that do not fit with the basic principles of good pain management.

## Conditions Affecting Nurses' Attitudes Toward Pain

Although the United States is made up of people whose ancestors immigrated from many countries, the development of social customs and practices for the country as a whole has been dominated by the group that came into power early, namely, the white, Anglo group from a predominantly Protestant background. All of us - no matter what our ethnic subgroup - have been profoundly influenced by a system of values and beliefs that has emphasized mastery over nature, individualism, and action rather than passivity.[20] With respect to pain, this Anglo group, which Zborowski labels the "Old American," places high value on emotional control and stoicism; his study shows that patients from this background define pain as a warning signal of illness, suggesting that active intervention is needed in order to remove some kind of mechanical difficulty in the body.[21]

It is probably fair to say that the bulk of nurses in the United States are white Americans who have been well socialized to believe that self-control in the face of pain is better than an open display of strong feelings of any kind. Nurses are also socialized into the subculture of nursing which, for its own special reasons, places high value on control of feeling and capacity to function capably under duress. Therefore, nurses as a class may be socialized even more than the ordinary individual to place high value on self-control in the face of pain.

In addition Petrie suggests that nurses as a class may be from the group of "moderates" whom she defines as people who neither subjectively increase nor subjectively decrease the sensory experience they receive.[22] Perhaps nurses, because of their own moderate responses to pain, are not highly sensitive to the pain reactions of patients who are either reducers or augmenters of pain experience. Alternately, of course, one might hypothesize that nurses (at least some of them) are initially sensitive to differences in pain in other people, but they become habituated to placing priorities on other kinds of sensory experience.

It is also conceivable that a person who tends to respond as a moderate sees and experiences a direct relationship between the amount of noxious stimulus and the amount of pain experienced, and, as a result, is susceptible to believing a simplistic stimulus-response model of pain response. That is, the person so oriented sees a direct relationship between the amount of organic pathology and the amount of pain experience. This person might also believe that there is one-to-one relationship between the intensity of pain and the amount of medication required to control it.

There is much to suggest that education for nursing means being trained to function in the acute care model of practice which includes, among other things, a controlled and highly limited use of analgesic and narcotic drugs for fear of addiction. The essence of this model of treatment is to use analgesic drugs on a short term basis with the expectation that the patient will recover and return to his normal function. The problem, of course, is that the acute care model makes a very poor fit with the basic needs of persons who have chronic and long term pain.

Although the dictum that nurses must not create drug addicts is clearly a part of basic nursing education, the emphasis probably stems from the dominant cultural influences which, in our judgment, reflect tremendous ambivalence about drug usage. With respect to the use of narcotic drugs in particular, many nurses appear also to have a great concern about giving the shot that puts "the patient over the edge." This extraordinary fear of an action which might be construed as euthanasia reflects the values of society in general. It is also evidence of the tremendously high value attached to life-saving activities within the medical and nursing worlds. For a complex combination of reasons, nurses may carry attitudes about pain that can interfere with their functioning effectively in assisting patients with cancer to find relief.

## Interferences with Effective Pain Management by Nurses

Although the attitudes of individual nurses clearly influence what they do in practice, there are other factors that can prevent effective pain management by nurses in the hospital. Very important, for example, is the reality of organizational factors, i.e. there is always more than one nurse involved in providing ongoing care and services to institutionalized patients. It is no secret to anyone that communication among three different shifts of workers is difficult, and, by and large, assignments in nursing have been task-centered rather than patient-centered. Use of the cancer nurse clinician to carry responsibility for patients can help - if the clinician has a good working relationship with the other members of the nursing staff on the unit. Even with efforts to involve the entire staff, there must ultimately be one person who carries responsibility for the decisions of clinical management if pain control is to be successful.

A second factor that can interfere with effective pain management by nurses is the authority issue exemplified in the phrase, "You'll have to ask your doctor." Although physicians may carry the legal responsibility for writing pain medication orders in the majority of places, nurses could assume far more responsibility for effective implementation of drug therapy in combination with other types of treatment measures. The problem for nurses seems to be unwillingness to accept responsibility for such decisions and to share them with physicians.

In a recent article on proper use of minor tranquilizers, hypnotics and sedatives, Morgan reminds us that the p.r.n. order gives the nurse the right to administer a drug if, in her independent judgment, such an action is the best one for the patient at that time. He also reminds us that health professionals, in general, seem to have rather simplistic attitudes about the use of these drugs - often manifest in these ways: the quiet floor, or "peace at any price" attitude, demonstrated by everybody having his sedative whether he wants it or not; the "raw guts" approach, also known as the "suffering is good" attitude - demonstrated by withholding medication as long as possible.[23]

A third factor that prevents nurses from providing effective pain management for cancer patients has to do with their personal reactions. Many nurses are badly misinformed about the relationships between cancer and pain. In addition, they may be badly uninformed about the variety of drugs, treatments, and other procedures that can be used either singly or in combination to assist people in finding relief from their discomfort. Perhaps most of all, however, effective pain management is prevented by attitudes that foster withdrawal from interactions with patients. The problem with cancer, of course, is that it triggers in all of us deep-seated fears about death and pain. Bakan asserts that pain does not exist until there is an organism that has been individuated; and that pain is always a reminder that death will eventually appear. In his very interesting analysis of relationships among disease, pain, and sacrifice, he points out that the ego needs the pain in order to function, yet its very functioning involves the attempt to rid itself of pain which is a reminder of death and personal annihilation.[24]

### The Difficult Problem of Changing Attitudes

In the course of becoming informed about pain and pain management, we have become acutely aware that attitudes toward pain may be the main impediments to improving pain management practices among nurses. Obviously, changing attitudes is not easy. Changing fundamental attitudes toward pain and response to pain could be a difficult problem in the socialization of people for health care work.

If it is indeed true that attitudes toward pain severely limit what nurses can do, could the "death" conferences approach serve as a model for dealing with the topic of pain? As many of you know, the last five years have seen a plethora of conferences dealing with death as a critical issue in health care practice - not an issue to be taken lightly, for the person who would learn to be a clinical artist in the care of the dying must be willing to come close to his own concerns and fears about death. In the same way, a confrontation with one's deepseated fears about pain would bring the individual close to his fundamental concerns about personal destruction and personal annihilation. As Bakan points out to us:

> *Pain is the common companion of birth and growth, disease and death, and is a phenomenon deeply intertwined with the very question of human existence. It is among the most salient of human experiences; and it often precipitates questioning the meaning of life itself.*[25]

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# DRUG THERAPY IN CANCER PAIN

Arthur G. Lipman, Pharm.D.

ABSTRACT An overview of drug therapy for chronic, severe pain due to cancer is presented. Differences between acute pain and chronic pain are described and the dimensions of severe chronic pain are presented as physical, psychological, and social. The necessity to treat each dimension is addressed as is the interplay between pain perception and anxiety. The use of non-narcotic analgesics is described in moderate, acute pain and chronic, aching pain. The effectiveness of commercially available non-narcotic analgesics is discussed. Narcotic analgesics are usually necessary in chronic, severe pain and equianalgesic doses of available narcotics are listed. Dosing regimens for narcotic analgesics are suggested. Tolerance and dependence do not commonly develop in patients with severe, chronic pain of physical origin and who receive appropriately dosed narcotics. Physiological and pharmacological reasons for this lack are discussed. Brompton's Cocktail and other narcotic analgesic combinations are discussed and are shown to be inappropriate. Appropriate adjunctive drugs to narcotic analgesics are discussed.

The most common fear associated with cancer is pain. Most people know, or know of, someone who has suffered excruciating pain due to cancer. Physicians, nurses, other health professionals and lay people tend to avoid patients with cancer, thus contributing to the patients' loneliness. Both the pain and the loneliness associated with cancer can be dealt with effectively. To do so, many health professionals must abandon much of what they currently believe about cancer and must become effective health educators as well as care-givers to cancer patients and their families.

In our experience, severe, chronic pain, the "agony" of cancer, occurs in only about 20% of patients who die due to neoplastic disease. But when that type of pain does occur, it so envelopes the patient's total existence that the pain becomes the focus of the existence. Patients in agony often do not retain their dignity. Care-givers and family members often cope poorly. The results are anger, frustration, and often psychological scars on those remaining after the patient dies.

But there is no need for most cancer patients to suffer such pain. We have the necessary medical, pharmacological, surgical, psychosocial, radiological and physical means today to make most cancer patients comfortable and to help them cope with their diseases and the resulting symptoms. It is extremely unfortunate that so many doctors, nurses, and others who take care of and interact with patients, maintain inappropriate and outdated beliefs about cancer, pain due to cancer, and analgesics.

Interdisciplinary pain teams often have been successful in managing pain that primary physicians alone could not control. The specialized skills of anesthesiologists, psychologists, social workers, surgeons, nurses, radiologists, pharmacists, physical and occupational therapists, and clergy are often valuable in designing and implementing regimes for the alleviation of seemingly intractable pain. Suboptimal pain control is sometimes provided to cancer patients due to their disease being diagnosed as terminal. The *a priori* ruling out of surgical, radiological, psychosocial, or other interventions due to a prognosis of a limited life span is inappropriate. The responsibility of health professionals and support persons is to help improve the quality of living in patients with advanced disease, not simply to help them to die. No reasonable approach to improving the quality of the patient's remaining life should be precluded due to the prognosis.

Drug therapy is one of the major modalities used in managing cancer pain. Drugs represent only one of many methods available and drugs are most effective when used in combination with other modalities. The best drug therapy without good psychosocial support is seldom very effective and the best loving care without appropriate drugs is usually not effective. Nerve blocks, local irradiation of painful tumors, palliative antineoplastic drug therapy, and other treatments should be used when necessary, in addition to the drug therapy approaches described in this paper.

## PAIN

Acute pain and chronic pain are very different problems and must be managed differently for optimal results.[6] Acute pain is a process which most persons have experienced. From childhood, people in most Western societies have been encouraged to be brave and bear pain without complaint. We think of pain as something that will pass quickly--and it usually does. We often rationalize pain as being inevitable--as in childbirth, as a part of the healing process, as after surgery, or as the result of our own folly--as after stubbing a toe. Health professionals are trained to encourage patients to bear such pain without drugs if possible. Nursing students are commonly taught that strong analgesics should be given only "prn" and then as sparingly as possible. Such beliefs and actions sometimes may be appropriate with acute pain. But they are usually highly counterproductive with chronic pain due to an active physical process such as tumor growth. Such chronic pain is pain that does not resolve quickly. It cannot be rationalized as normal or as a clinical monitoring parameter. With chronic cancer pain, the patient often sees his/her body failing rapidly and this can exacerbate the pain. Analgesics that have been ordered on a "prn" basis are frequently demanded more frequently than the orders permit. Anxiety about the pain increases the patient's perception of the pain, and the continued presence of the pain produces more anxiety. Reactive depression may complicate the situation with disturbances in sleep and eating habits. The patient's behavior discourages visits by friends and family members and favors avoidance by nurses and doctors. Loneliness results and this dimension increases the complexity of the patient's misery.

Acute pain can be classified as mild, moderate, or severe. Chronic pain cannot be so easily described. Rather, chronic pain is better expressed as a circular continuum from aching to agony (Fig. 1). The agony phase is the severe, chronic pain which often requires pharmacological, psychological, and social support to manage. The objective of treating such pain is not to

Figure 1

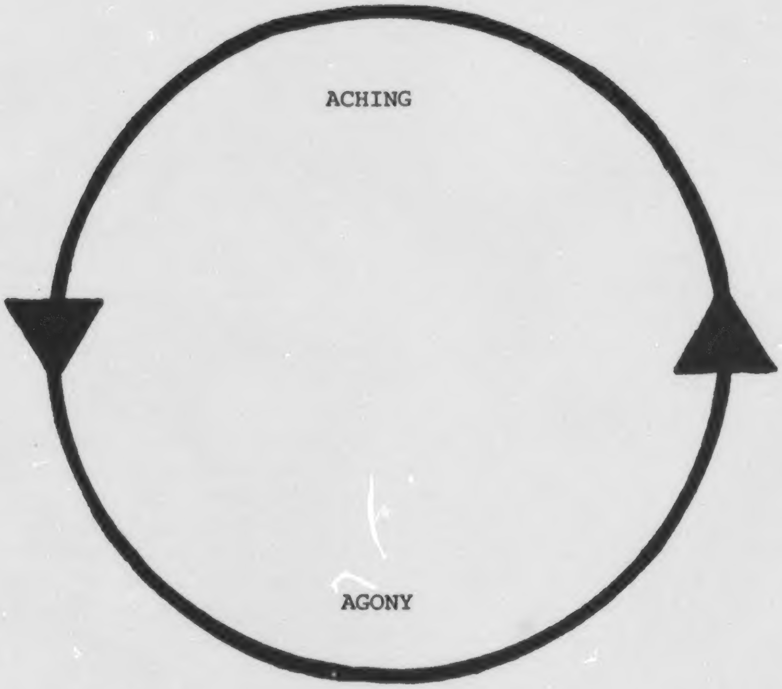

Fig. 1. The continuum of chronic pain. Adapted from: Lipman, A.G., Drug therapy in terminally ill patients (Am J Hosp Pharm 32:270-271, 1975).

eliminate it, but to reduce it to the aching phase with which the patient is usually able to cope. Some patients will experience aching on one day, agony the next, and aching the third. The shifts may be due to psychological factors with no change in the patient's physical condition. Such variations in chronic pain are common, but they are often not understood by nurses and other observers. As a result, the patients are sometimes labeled as "complainers" or "crocks" when they are really suffering. The major etiological difference between chronic aching and chronic agony may be that the former is primarily due to physical causes, while the latter has greater psychological and social dimensions.

## The Dimensions of Chronic Pain

There are three dimensions to severe, chronic pain.[7] These are physical, psychological, and social (Fig. 2). The physical dimension of chronic cancer pain is quite variable. Pain may be minor for a period of time followed by major, but short-lived, exacerbations such as may occur with bony metastases. The physical component of pain may increase or decrease over time.

Continual physical pain produces anxiety. Mixed anxiety-depression is also commonly seen. Patients with cancer frequently develop reactive depression to the realization of their disease also. Thus, the psychological dimension of pain is seen. The affective component of pain has been demonstrated in patients with asymbolia for pain.[13] Such patients receive pain stimuli, but they do not experience the hurt that others feel. These subjects can recognize the physical stimuli, but they do not experience the emotional reactions that are seen with normal subjects. Thus, the physical hurting of pain produces the psychological component of pain. The psychological component is not seen in individuals for whom pain stimuli do not cause hurting.

When pain persists for an extended period of time, the social dimension of pain may also be seen. The patient's anxiety and depression result in deviation from normal sleeping, eating, and social interactions. Patients become more hostile and this often results in avoidance of the patient. Thus patients feel isolated and this may increase their hostility.

The clinical presentation of a patient with severe, chronic pain may thus be complex. Such a presentation is expressed in Figure 3.

## Analgesics

Since many cancer patients do not experience severe, chronic pain, it should not be assumed that only the most potent analgesics should be used in cancer pain. The selection and dosing of analgesics must be made for the specific patients' needs. Individualization and titration for effect are in order.

There are three levels of analgesia that can be achieved with drugs. These levels correspond to the acute pain classifications of mild, moderate,

FIGURE 2

DIMENSIONS OF SEVERE, CHRONIC PAIN

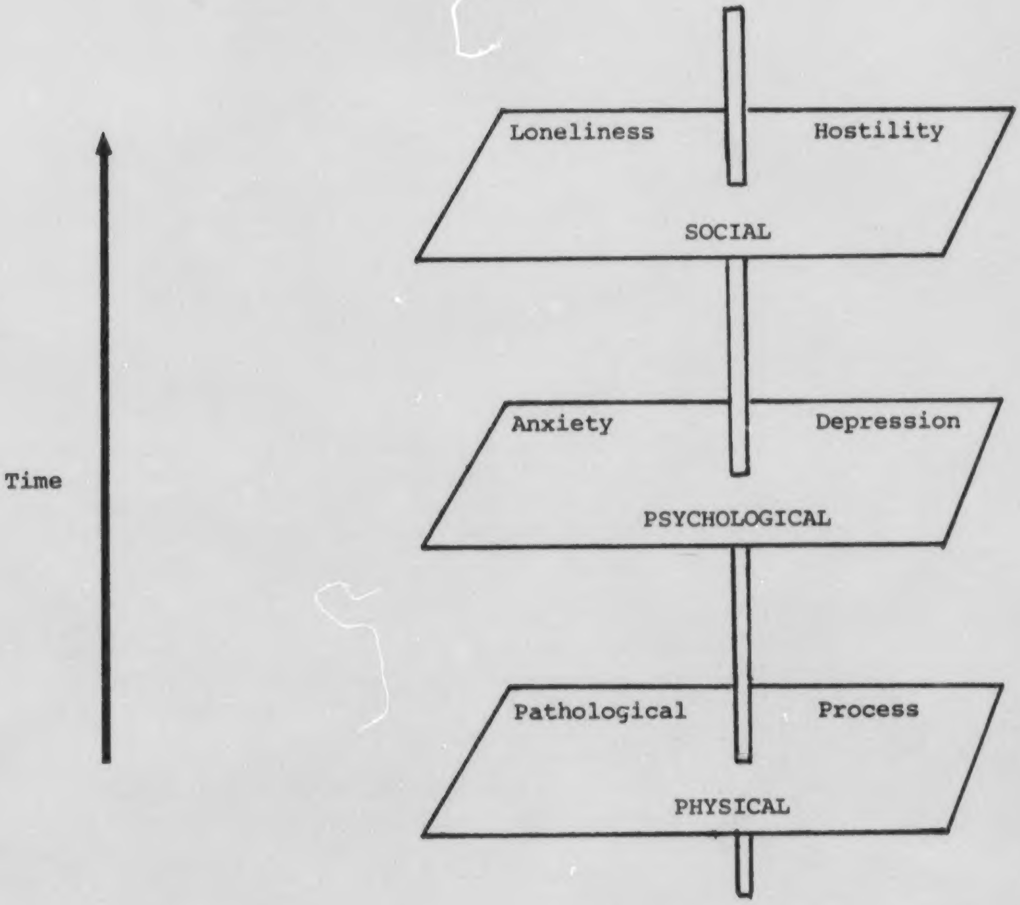
Loneliness
Hostility
SOCIAL
Anxiety
Depression
PSYCHOLOGICAL
Time
Pathological
Process
PHYSICAL

Fig. 2. Dimensions of severe, chronic pain. Adapted from: Lipman, A.G., Drug therapy in chronic pain (J Cont Ed Clin Hosp Pharm 1: 1979).

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FIGURE 3

## THE PRESENTATION OF SEVERE, CHRONIC PAIN

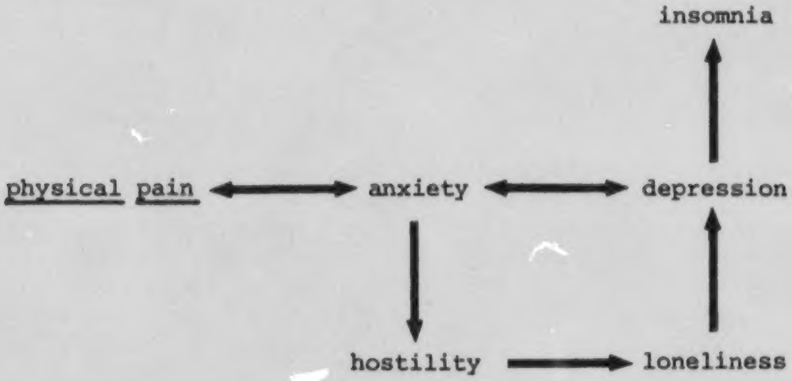

insomnia
physical pain
anxiety
depression
hostility
loneliness

Fig. 3. The preservation of severe, chronic pain.

and severe. Pharmacologically, there is no more effective single analgesic for mild to moderate pain than aspirin. However, pain is a highly subjective phenomenon. If the patient believes that propoxyphene (Darvon ® ) and codeine are more potent than aspirin, the patient may experience more analgesia from propoxyphene or codeine than from aspirin.

There is an additive, and perhaps synergistic, effect between aspirin and codeine or oxycodone. Thus such combinations as Ascodeen ® (aspirin plus codeine) or Percodan®(aspirin, phenacetin, caffeine, and oxycodone) are useful in moderate, acute pain. Either aspirin alone or one of these combinations may be sufficient for management of chronic, aching pain. Codeine and oxycodone are narcotics. These two drugs produce analgesia similar to that achieved with low-dose morphine. But codeine and oxycodone may not produce increasing analgesia with increasing doses as does morphine. Therefore, codeine and drugs such as Percodan® are not advocated in severe, chronic pain.

Few good, comparative studies of non-narcotic analgesics have been reported. One double-blind, crossover, single-dose study of commercially available analgesics in moderate cancer pain[10] documented that aspirin 650 mg was superior to mefenamic acid (Ponstel® ) 250 mg, pentazocine (Talwin® ) 60 mg, acetaminophen (Tylenol ® , Datril ® , others) 650 mg, phenacetin 650 mg, and codeine 60 mg. All of the drugs studied were superior to placebo. In the same study, propoxyphene hydrochloride (Darvon ® - 65) 65 mg, ethoheptazine (Zactane ® ) 75 mg, and promazine (Sparine ® ) 25 mg were shown to not produce analgesic efficacy. A later, double-blind, crossover, single-dose study of the efficacy of commercially available analgesic combinations in 100 patients[11] with chronic, recurring cancer pain documented that the combinations listed in Table I were superior to 650 mg of aspirin, while those in Table II offered no advantage over aspirin alone.

The most potent analgesics that we have available are the narcotics (with the exception of codeine and oxycodone). In severe, chronic pain, these drugs are nearly always the analgesics of choice. There are no significant clinical differences between the various drugs in potency or in side effects. There are significant differences in the durations of action.[8] Each of the commercially available narcotic analgesics listed in Table III will produce similar analgesia if administered in the appropriate dose at the appropriate time interval. In chronic pain management, drugs with a longer duration of action are usually preferred.

Any narcotic analgesic may produce accumulation several days to weeks after initiation of therapy resulting in undesired sedation or other signs of CNS depression. This is particularly true of the more lipophilic drugs such as levorphanol (LevoDromoran ® ) and methadone (Dolophine ® ). This effect is more apt to occur in elderly than young patients.[17] Therefore, it is generally safer to raise a narcotic dose by increasing the amount of drug per dose than by decreasing the dosage intervals below those listed in Table III. In this way, an insidious onset of accumulation is less apt to occur. The literature on equipotent narcotic doses is inconsistent. The doses listed in Table III are based on both some of the published

## Table I*

### Analgesic Combinations Found Superior to Aspirin, 650 mg

Codeine sulfate, 65 mg plus aspirin 650 mg
Pentazocine hydrochloride 25 mg plus aspirin 650 mg
Oxycodone 9 mg plus aspirin 650 mg

*Adapted from: Moertel, C.G., Ahmann, D.G., et al.: Relief of pain by oral medications (J AM Med Assoc 229:55-59, 1974)

## Table II*

### Analgesic Combination That Produced No Significant Difference from Aspirin 650 mg

Propoxyphene napsylate 100 mg plus aspirin 650 mg
Ethoheptazine citrate 75 mg plus aspirin 650 mg
Promazine hydrochloride 75 mg plus aspirin 650 mg
Pentobarbital sodium 32 mg plus aspirin 650 mg
Caffeine 65 mg plus aspirin 650 mg

*Adapted from: Moertel, C.G., Ahmann, D.L., et al.: Relief of pain by oral medications (J Am Med Assoc 229:55-59, 1974).

## Table III

### Narcotic Analgesics: Approximate Equanalgesic Doses of Selected Commercially Available Dosage Forms

| Drug | Route | Dose (mg) | Average Duration of Action (hours) |
|---|---|---|---|
| Hydromorphone (Dilaudid®) | PO | 3-4 | 3-4 |
| | PR | 3-6 | 3-4 |
| | I.M., SC | 2-3 | 3-4 |
| | I.V. | 2 | 3-4 |
| Levorphanol (LevoDromoran®) | PO | 2-3 | 6-8 |
| | SC | 2 | 6-8 |
| | I.V. | 2 | 4-6 |
| Meperidine | PO | 100-150 | 3 |
| | I.M., SC | 75-100 | 3 |
| Methadone (Dolophine®) | PO | 12.5 | 6-8 |
| | I.M., SC | 10 | 4-6 |
| Morphine sulfate | PO | 15 | 3-4 |
| | I.M., SC | 10 | 4-6 |
| | I.V. | 8 | 3-4 |
| Oxymorphone (Numorphan®) | PR | 2-5 | 4 |
| | I.M. | 1-1.5 | 4 |

literature and the author's clinical experience.

## Tolerance and Dependence

Most nurses and other health professionals were taught that narcotic analgesics produce rapid tolerance necessitating frequent increases in dose to maintain effect, and that continuation of narcotics for more than a few days may produce dependence. Physicians often consider these factors when prescribing narcotics. While tolerance and dependence are sometimes seen in patients who receive narcotics for pain of an acute or psychosomatic nature, these phenomena are less common with severe, chronic pain for which there is a physical cause, e.g., tumor growth and when appropriate dosing is employed.

Patients with severe, chronic pain react differently to narcotic analgesics than do drug abusers who seek euphoric effects of narcotics or patients who receive narcotics for pain of primarily psychogenic orgin. Recent studies have demonstrated the presence of opiate receptors in the central nervous system and of endogenous opioid substances called enkephalins.[16] Patients who have pain due to physical causes may have high titers of free endogenous opioids in their bodies. Such patients' physiological processes differ from persons not experiencing physical pain. The changed physiological state may well result in different pharmacological responses to narcotics than would be experienced by persons not experiencing physical pain.

Little tolerance to narcotics develops in patients with chronic pain due to active physical pain-producing processes. Variations in doses are indicated as the disease progresses or remits, but continually increasing dose requirements due to tolerance seldom occur. Reports of cancer patients receiving relatively constant doses of narcotics for periods of 50 to 100 weeks resulting in successful management of pain have demonstrated that tolerance does not occur in such patients.[19]

Dependence likewise is not a problem in patients who receive appropriately dosed narcotic analgesics for chronic, sever cancer pain. It is not necessarily to attempt to rationalize dependence due to the disease being terminal. Dependence is not a significant problem when the drugs are being used appropriately to treat pain of physical origin.

## Narcotic Dosing

There are three important principles in the dosing of narcotic analgesics. The first is that the optimal dose should be determined by titration for effect. Seemingly hugh doses may be necessary to obtain initial pain control in a patient with severe, chronic pain. Patients who have such pain may not only tolerate, but also need, such doses for analgesia. The doses may seem inappropriately high if thought of in terms of acute pain doses. But the chronic pain patient's respiration, pulse, and other signs often remain normal or only slightly depressed by the high dose. Patients who have been experiencing severe pain for many days will often sleep for extended periods after receiving an adequate dose of analgesic. The sleep is not necessarily indicative of an overdose. Severe pain is exhausting and precludes sleep. The extended sleep is appropriate and needed.

The second principal is that it is better to start with a dose that is a little too high than one that is too low. If a low initial dose is used with the intent to titrate upward, the patient often experiences increasing anxiety due to lack of sufficient analgesia in spite of the fact that a narcotic is being administered. This anxiety may exacerbate the pain and necessitate a higher dose being needed for analgesia than would have been the case if a slightly higher dose had been used initially.

The third and most important principal is that the narcotic should be administered on a regularly scheduled basis, not "prn." Prevention of the recurrence of pain lessens anxiety about the pain. This may be achieved by administering each dose of the drug before the previous dose loses effect. Prevention of pain recurrence usually requires less analgesic than treatment of pain after it has recurred. Dr. Cicely Saunders, a leader in developing programs of palliative care for seriously ill cancer patients, has written about chronic, severe pain:

> Such pain calls for continuous control, and drugs must be given regularly. Pain itself is the strongest antagonist to analgesia, and it should be kept in constant remission. If treatment anticipates pain, the patient will not anticipate pain and will not continually increase it by fear and tension.

When the initial dose of narcotic analgesic is selected, the clinician must consider the severity of pain, prior analgesic drug use, the patient's body weight, and the patient's ability to eliminate the drug (primarily kidney function). Oral therapy is preferred due to the obvious psychological advantages of not needing injections. Generally, patients able to take nourishment orally can achieve analgesia by this route. Rectal suppositories of several narcotic analgesics are available for administration of drug by an alternate enteral route. Although parenteral therapy produces higher initial serum and tissue levels, oral doses are as effective as parenteral doses in maintaining drug levels in the body. Intramuscular and subcutaneous injection is difficult and painful in patients with marked muscle wasting. Furthermore, parenteral administration creates a feeling of patient dependence on others for administration of the drugs. Parenteral administration may also intimate that heroic measures are being undertaken.

Morphine is commonly believed to be a poor drug for oral use. This is untrue.[20] Although morphine is only about two-thirds absorbed following oral administration, this effect may be obviated by adjusting the dose. Fifteen mg of oral morphine sulfate is as effective as a 10-mg parenteral dose.

Methadone is an excellent oral drug to use due to its commercial availability as both 5- and 10-mg scored tablets and its relatively long duration of action. Once initial pain control is achieved, analgesia may usually be maintained with a dose every 8 hours. It is usually not necessary, therefore, to awaken a sleeping patient for a nighttime dose.

The initial dose of a narcotic analgesic should be relatively high as discussed above. Once initial pain control is achieved, the dose can usually be lowered without loss of effectiveness. This is probably due to the patient's anxiety about the pain being lessened after pain control is achieved. The optimal dose is the lowest dose which prevents recurrence of the pain. This dose is found by reducing the amount of drug slightly every 2-3 days until the dose is insufficient to control pain. The optimal dose is usually between the last effective dose and the insufficient one (Fig. 4). This dose may be effective for an extended period of time or an increase may be needed soon due to progress of the disease or an additional source of pain. The dose should be increased as needed, but once an effective dose is reestablished, the clinician should once again attempt to lower it to an optimal dose.

Analgesic Drug Cocktails

Scientific study of the efficacy of Brompton's Cocktail and other highly touted narcotic mixtures and of heroin has only begun in earnest in this decade. As recently as 1970, leading European[19] and North American[12] clinicians were advocating the use of Brompton's Cocktail as the analgesic of choice in advanced cancer pain and a noted political columnist[1] was demanding that herion be legalized for analgesia in the United States. There is no scientific foundation to the claims of superior efficacy of these drugs. Recent controlled studies have shown that neither Brompton's Cocktail nor heroin has any advantage over morphine as analgesics.[22,23]

The use of narcotic containing multiple drug cocktails in severe pain dates from the late 19th century when Snow, a surgeon at the Cancer Hospital, London (now The Royal Marsden Hospital), reported the use of morphine and cocaine in advanced cancer.[15] He later deleted the cocaine due to its expense. In the 1920's, Roberts, a surgeon at the Brompton Hospital in London, reintroduced a morphine-cocaine mixture for analgesia following thoracotomy. Other combination analgesic formulations became popular in later years and in 1952, the Brompton Hospital published a pharmacopoeial supplement containing the following formulation named "Haustas E."[9]

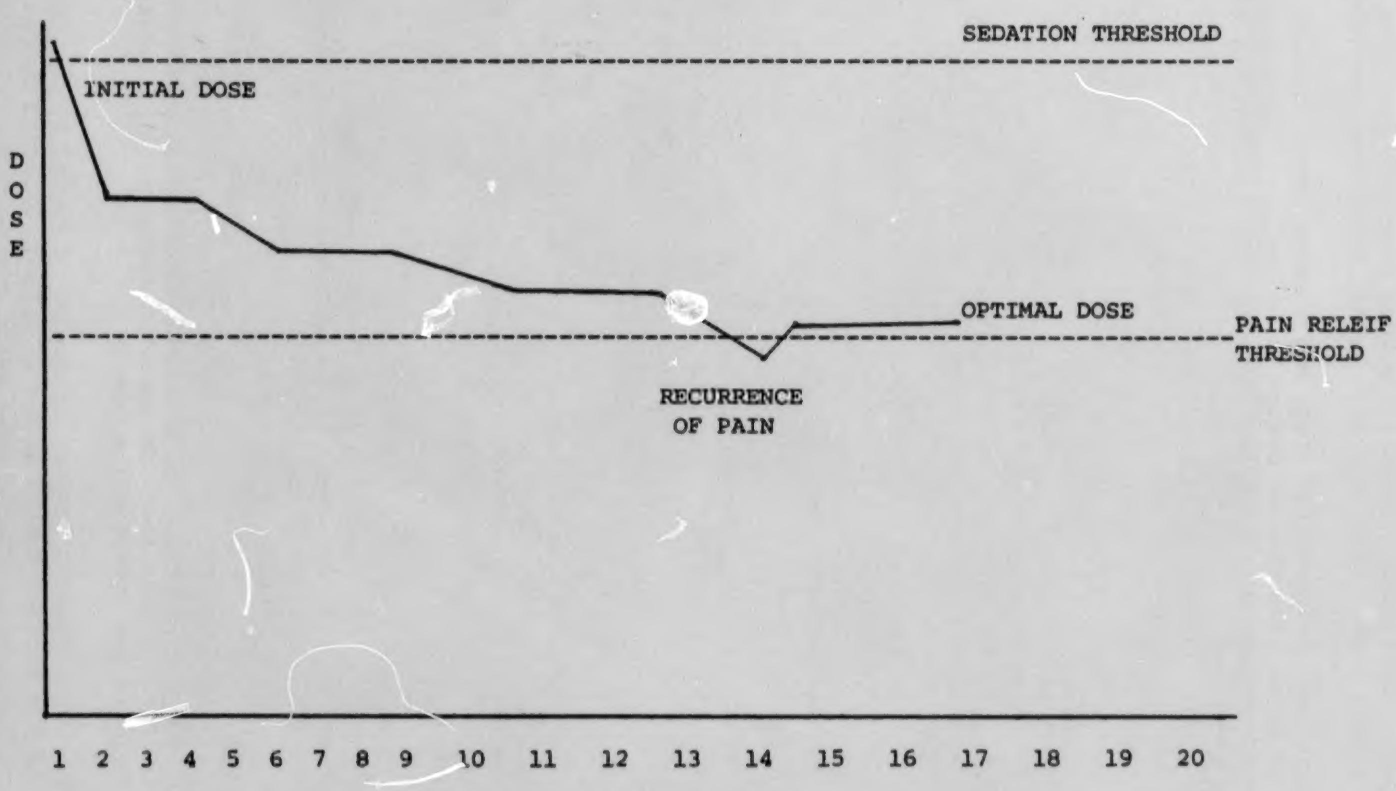
| | |
|---|---|
| Morphine HCl | 15 mg |
| Cocaine HCl | 10 mg |
| Alcohol 90% | 2 ml |
| Syrup | 4 ml |
| Chloroform water q.s. ad. | 15 ml |

Later formulations substituted diamorphine for the morphine. Such formulations have been called Hospice Mix, Saunder's Solution, Euphoriant solution, and Brompton's Mixture. It should be noted that Brompton's Mixture is a cough preparation, not an analgesic, and it contains morphine, hydrocyanic acid, syrup of tolu, and flavoring.[9]

FIGURE 4

NARCOTIC DOSE TITRATION

(From reference 9)



The British Pharmacopeial Codex of 1973 included diamorphine and cocaine elixir. This formulation was listed in an effort to standardize the several opiate-cocaine formulations then being used in the United Kingdom.[18 21] Several opiate combination formulations have come into use in the United States in recent years. Most are irrational, expensive, and unnecessary.

A controlled, double-blind study has been reported in which morphine was shown to be as effective an analgesic as herion.[23] Unfortunately, public groups and state and federal legislatures are still attempting to legalize heroin for use as an analgesic in this country. Heroin offers no therapeutic advantage over the commercially available narcotic analgesics. But because of its ability to produce a euphoric "rush" following intravenous administration, the abuse of heroin and the potential for the diversion of the drug into illicit channels is great.

Cocaine is not additive to the analgesic effect of narcotic analgesics as reported in a recent controlled, double-blind study.[22] Cocaine was added to the original Brompton's Cocktail as a local analgesic for the throat and/or to relieve some of the sedation produced by the narcotic. The former suggested indication may be appropriate in some pulmonary disease patients (the Brompton Hospital is an institution primarily for chest disease), but is not applicable to most pain patients. The later indication is not appropriate because titration of the narcotic dose, as described above, results in minimal sedation from the analgesic.

A third component of many opiate cocktails is alcohol. Alcohol is an additive central nervous system depressant to the narcotic, but the addition of the alcohol offers no pharmacological or therapeutic advantage. Since the narcotic dose is titrated to effect, the addition of alcohol may allow the use of less narcotic, but the alcohol provides no advantage in safety or efficacy.

The fourth common ingredient of many British opiate mixtures in the past has been chloroform water. This agent was added to impart a medicinal taste. Chloroform has been implicated as a carcinogen and has been removed from the American GRAS list (agents generally regarded as safe for use in drugs, food, and cosmetics).

A common expectation of English patients is that drugs be in bitter tasting liquids. The opiate cocktails fulfill these expectations. The common American expectation is that drugs be as oral, solid dosage forms or as sweet tasting liquids. The attempts of many Americans to adapt British formulations in this country are inappropriate.

Other narcotic combinations such as Schlesinger's Solution may be likewise shown to be irrational. There is no pharmaceutic or therapeutic rationale for administering more than one narcotic analgesic to a patient. Neither decreased toxicity nor potentiation occur.

Both St. Christopher's Hospice in London, directed by Dr. Cicely Saunders, and Sir Michael Sobell House in Oxford, directed by Dr. Robert

Twycross, now use simple aqueous solutions of morphine as their primary narcotic analgesic. Dr. Saunders is a pioneer in symptomatic care for patients with advanced cancer symptoms and Dr. Twycross is the clinical pharmacologist who has published the most definitive data on advanced cancer pain. Neither of them any longer advocates the use of heroin or Brompton's Cocktail over simple narcotic analgesics that are commercially available in the United States.[24]

## Adjunctive Drugs

The principal adjunct to narcotics in severe, chronic pain is a phenothiazine. There are three reasons for adding this drug. The first is that high doses of narcotics often induce nausea. The nausea may become a major problem, but more often it is low grade and simply adds to the patient's feeling of not well being. Phenothiazines are among the most effective antiemetics available. The second reason is that low-dose phenothiazines provide antianxiety activity. The third reason is that the combining of a phenothiazine with a narcotic has been claimed to allow the use of a lower dose of the narcotic without loss of effectiveness. Some mild reduction in narcotic induced respiratory depression and constipation may result, but the therapeutic gain is minimal.

Some clinicians have successfully used benzodiazepine (chlordiazepoxide-Librium ®, Diazepam - Valium ® ) adjuncts for the antianxiety activity, but these drugs do not provide antimetic action.

Commercially available phenothiazines may be classified according to the chemical side chain on the phenothiazine nucleus. The alkylamino side chain phenothiazines which include chloropromazine (Thorazine® , others) and promethazine (Phenergan ® ) are quite sedating. Sedation is generally not desired since the narcotics are also sedating. An alkylamino side chain phenothiazine adjunct may be useful in an agitated patient, however. The piperidine side chain phenothiazines may produce more parasympatholytic (anticholinergic) activity than the other types. This effect is also undesirable since the narcotics are constipating and additional constipating drugs may result in fecal impaction. The two drugs in this group that are available in this country are thioridazine (Mellaril ® ) and mesoridazine (Serentil ® ). The piperazine side chain phenothiazines, e.g., prochlorperazine (Compazine ® ), are preferred. These drugs also produce some anticholinergic effects, but these effects are less than with the piperidine group and no more than with the alkylamino group. In high doses, the piperazine phenothiazines may cause extrapyramidal symptoms and dysphoria. For use as narcotic adjuncts, low doses are indicated. This group of phenothiazines offers the advantages of minimal sedation and maximal antiemetic activity. A typical drug and dose would be prochloroperazine, 5 mg every 8 hours.

Reactive depression may accompany chronic pain of extended duration. The depression often resolves when the anxiety diminishes however, and pharmacological intervention for the depression often is not indicated.

Tricyclic antidepressants such as imipramine (Tofranil®, others) and amytriptyline (Elavil®, others) are not optimally effective in exogenous depression and the drugs have significant anticholinergic effects. Management of the pain and anxiety usually diminishes the depression, but if the depression becomes a major problem in itself, antidepressant drug therapy should be considered.

Narcotic and anticholinergic drugs are constipating. Constipation is a problem for some patients taking narcotics. Adequate oral hydration may lessen this problem, but laxatives may be needed. Bulk producing cathartics such as psyllium as in Metamucil® are in the safest drugs but they may not be effective due to diminished peristaltic tone. If bulk producers are not effective, stimulating agents such as bisacodyl (Dulcolax®, others) should be used. Stool softeners such as dioctyl sodium sulfosuccinate (Colace®) are generally effective in patients with diminished peristalsis.

The phenothiazine adjunct is generally sufficient to control narcotic-induced nausea. Occasionally, patients do not respond to the phenothiazines alone. In such cases, one should consider adding an antihistaminic antiemetic such as cyclizine (Marazine®) or dimenhydrinate (Dramamine®) to the phenothiazine. The antihistamine drug acts on the vestibular source[5] of nausea while the phenothiazine acts on the medullary source.[2] Narcotics may induce nausea through both mechanisms.

## Conclusion

The management of severe, chronic pain is now possible for most patients with cancer. Narcotic analgesics and adjuncts that are commercially available in the United States are highly effective. Intelligent use of these drugs, combined with other modalities as needed, and with good psychological and social support usually results in the patient being reasonably comfortable and not overly sedated. Experimental use of marijuana (DELTA-9-tetrahydrocannabinol)[3] and other illicit drugs has not been shown to be of significant help in most patients. Heroin has been shown to offer no advantage over morphine or methadone orally, although some clinicians continue to advocate heroin when a high-dose parenteral narcotic is needed.[4] This is due to heroin being more water soluble than other narcotics, thus allowing an injection of a lower volume to be given.

It is necessary to design and adjust each cancer patient's pain drug regimen for the patient's changing needs. Tolerance and dependence need not be major concerns with narcotic analgesic use. Multiple drug therapy due to multiple problems is often indicated, resulting in an increased risk of drug interactions. Dose and drug changes are often indicated when advancing disease affects the patient's physiological ability to absorb, distribute, metabolize or excrete drugs. Special dosage forms may be needed for specific patients. Pharmacists can often be of assistance in the monitoring of drug therapy and in suggesting or formulating special dosage forms.

Nurses are in an excellent position to provide psychological and social as well as medical support to cancer patients. Health professionals' willingness to listen to patients' concerns and to help to explain physiological and pharmacological effects can be very helpful to cancer patients and their families. With increasing research and experience in the management of severe, chronic pain, effective and new approaches to its management are becoming available.

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# MODULE VII-B PAIN AND SYMPTOM MANAGEMENT

## PARTICIPANT MANUAL

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# MODULE VII-B: PAIN AND SYMPTOM MANAGEMENT

## PURPOSE AND GOALS

The purpose of Module VII-B is to assist the hospice care nurse to intervene more effectively to relieve the symptoms experienced by patients. The goals of this module are to assist participants to:

- Identify factors which contribute to the symptoms experienced by patients
- Develop alternative interventions to provide symptom relief
- Evaluate the effectiveness of interventions

## MODULE CONTENT

The Module Content includes the following areas:

- Overview: Symptom Management
- Pain
    - Causes of pain
    - Attitudes related to pain
    - Assessment of pain
    - Interventions to modify pain
- Nutritional Impairments and Related Problems
    - Rationale
    - Anorexia
    - Nausea, Vomiting
    - Taste Disturbances
    - Stomatitis
    - Nutritional Assessment
    - Strategies for Modifying Food Intake
- Problems of Elimination - Bowel
- Incontinence

- Problems Related to/Resulting in Immobility
    - Edema
    - Thrombophlebitis
    - Decubiti
    - Pathologic Fractures
- Infection
- Fatigue
- Dyspnea

## LEARNING OBJECTIVES

Using the information presented in this module as criteria, at the end of this module, and without aid of notes, participants will be able to:

1. Identify factors which contribute to the symptoms of pain, anorexia nausea/vomiting, taste disturbances, stomatitis, constipation, diarrhea, incontinence, edema, thrombophlebitis, decubiti, pathologic fractures, infection, fatigue and dyspnea.
2. Describe relationships between symptoms.
3. Suggest data which are necessary to obtain to be able to plan interventions for the symptoms of pain, anorexia, nausea/vomiting, taste disturbances, stomatitis, constipation, diarrhea, incontinence, edema, thrombophlebitis, decubiti, pathologic fractures, infection, fatigue and dyspnea.
4. Suggest alternative interventions to provide relief from the symptoms of pain, anorexia, nausea/vomiting, taste disturbances, stomatitis, constipation, diarrhea, incontinence, edema, thrombophlebitis, decubiti, pathologic fractures, infection, fatigue and dyspnea.
5. Identify side effects of interventions.
6. Evaluate the appropriateness of interventions for the individual patient.
7. Evaluate the effectiveness of specific interventions.

## PERSPECTIVE

Symptom management can be an appropriate and rewarding focus for nursing. Regardless of the progress of a disease, there is always something that can be done to at least partially improve symptomatology. Essential to this process are clear problem identification, realistic goal setting and creative problem solving. This module attempts to provide the nurse with the necessary information to be able to help patients/families/caregivers define symptom related problems more clearly and set realistic goals. The emphasis, however, is on developing a pool of interventions for specific problems from which the nurse is able to draw.

Pain and nutritional problems are emphasized both because they constitute the most common and most distressing problems but also because there are so many things that can be done that are often not done in these areas.

This module is addressed to the nurse. This does not suggest that utilization of a team approach is not considered. But, a nurse does have the background and skill to do all that is suggested. Utilizing other team members will increase the likelihood of clear problem identification as well as the kinds of alternatives available for care. However, even in those situations where the nurse does not have any resources readily available, much can be done. And, even when a multidisciplinary team is in operation there is no reason for the nurse to be lacking in knowledge of aspects of critical importance to total patient care.

## MODULE ORGANIZATION

Module VII-B is different than the other modules of this curriculum in that the instructional materials are in the Instructors Manual rather than the Participant Manual. The reason for this is that Module VII-B is designed specifically for the learning needs of each new participant group.

Complete the knowledge and skill inventory on the following page. Your Instructors will review the inventories for your group, select those symptoms to receive greatest emphasis in the module, and provide you with the handouts and materials for the module.

## PAIN AND SYMPTOM MANAGEMENT
## KNOWLEDGE AND SKILL INVENTORY

Listed below are fifteen symptoms or conditions the hospice nurse is called upon to manage. Reflect on your education, training and experience in managing each of these symptoms. Indicate those symptoms you feel should receive the greatest emphasis during Module VII-B. Circle the number below that indicates your need for information on the assessment and management of each of the symptoms.

Circle the appropriate rating for each symptom

| | Least Emphasis | Less Emphasis | Emphasize | More Emphasis | Most Emphasis |
|---|---|---|---|---|---|
| Symptom/Condition | 1 | 2 | 3 | 4 | 5 |
| 1. Pain | 1 | 2 | 3 | 4 | 5 |
| 2. Anorexia | 1 | 2 | 3 | 4 | 5 |
| 3. Nausea/Vomiting | 1 | 2 | 3 | 4 | 5 |
| 4. Taste disturbances | 1 | 2 | 3 | 4 | 5 |
| 5. Stomatitis | 1 | 2 | 3 | 4 | 5 |
| 6. Constipation | 1 | 2 | 3 | 4 | 5 |
| 7. Diarrhea | 1 | 2 | 3 | 4 | 5 |
| 8. Incontinence | 1 | 2 | 3 | 4 | 5 |
| 9. Edema | 1 | 2 | 3 | 4 | 5 |
| 10. Thrombophlebitis | 1 | 2 | 3 | 4 | 5 |
| 11. Decubiti | 1 | 2 | 3 | 4 | 5 |
| 12. Pathological fractures | 1 | 2 | 3 | 4 | 5 |
| 13. Infection | 1 | 2 | 3 | 4 | 5 |
| 14. Fatigue | 1 | 2 | 3 | 4 | 5 |
| 15. Dyspnea | 1 | 2 | 3 | 4 | 5 |

# MODULE VIII: INTERDISCIPLINARY TEAM

## PARTICIPANT MANUAL

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# MODULE VIII: INTERDISCIPLINARY TEAM

## I. INTRODUCTION AND PURPOSE

During recent years health care systems and the knowledge base necessary for the provision of holistic care have increased in volume and complexity. As a result, new professional groups have developed to meet the multiple demands of patient and family care. As these professions have begun to work together to deliver comprehensive health care, the concept of the interdisciplinary team has evolved. Yet many questions need to be raised concerning this concept. Some of these are: What is an interdisciplinary team? What are the advantages and disadvantages of team work? What specific knowledge must each team member possess to participate in the team? How does the team approach effect the individual's professional responsibility for patient care?

The purpose of Module VIII is to develop a framework for interdisciplinary team concepts which will enhance the nurse's understanding of and participation in the hospice health care team.

## II. CONTENT

The module content includes the following areas:

- Operational definitions of an interdisciplinary team
- Components of team work
- The team as a small group
- Composition of the team in the hospice care setting: knowledge, roles and conflicts
- The environmental impact on team functioning
- The patient and family as team members
- Process analysis of each participants individual participation in working with members of the interdisciplinary team
- Process analysis of the hospice care team, utilizing the team development model by Lowe/Herranen

## III. LEARNING OBJECTIVES

At the end of Module VIII participants will be able to:

- Describe two definitions of a team
- Discuss the components of team work as follows:

a. Discuss internal and external role expectations as related to the hospice nurse

b. List and describe three types of decision-making that influence team functioning

c. List and discuss three different leadership styles that influence team functioning

d. Identify communication patterns most prevalent in hospice care team, and discuss the impact of these patterns on goal/task achievement

e. Identify four group norms observed in the hospice care team

f. Describe how goals/tasks evolve at a team meeting

- Describe and discuss group behavior that can be observed in team setting
- Describe and discuss the roles of hospice team members, and identify areas of overlap between members
- Describe the role of conflict as it relates to group productivity and goal outcome
- List and describe four ways the hospice environment effects team functioning
- Describe and critique the role of the patient and family as team members
- Discuss and critique value dilemmas encountered by the nurses on the hospice care team
- List and discuss three individual behaviors which enhance and inhibit team work
- Utilizing one interdisciplinary interaction the participant has been involved in, analyze and assess his/her own behavior and reactions as a team member
- Describe and analyze the hospice care team from the trainee's perspective utilizing the team model by Lowe/Herranen

# SECTION 1: OVERVIEW OF INTERDISCIPLINARY TEAM CONCEPTS

**Exercise 1:** Team Statement Form

**Purpose:** To delineate the participants' current perceptions of team work

**Instructions:** Read each statement in Exhibit VIII A and answer true or false.

**Exercise 2:** Definition of an Interdisciplinary Team

**Purpose:** To define an interdisciplinary team from the participants' point of view

**Instructions:** Write on a sheet of paper your definition of an interdisciplinary team.

Exhibit VIII-A

## TEAM STATEMENT FORM

Read each statement carefully and then write A (Agree) or D (Disagree) in space before question.

_____ 1. Team work ensures good patient care.

_____ 2. Patients should not be members of the interdisciplinary team.

_____ 3. Even a minor intervention with patient/family should be reported at team meeting.

_____ 4. Conflict is always destructive to team productivity.

_____ 5. Ethical and value dilemmas are best handled privately rather than at team meetings.

_____ 6. Role overlap is beneficial to team work.

_____ 7. Skills in teamwork are an innate part of each professional's training.

_____ 8. Team work implies equal status for all members.

_____ 9. Teamwork implies that members must always compromise in order to function effectively.

_____ 10. Team functioning is not possible unless all members are present.

## DEFINITIONS OF AN INTERDISCIPLINARY TEAM

There are many definitions of an interdisciplinary team. The following are representative of the literature:

1. Teamwork occurs when "a number of associates all subordinate personal prominence to the efficiency of the whole." (Rae-Grant and Marcuse 1968, p. 4).

2. "A team is a group of people each of whom possess particular expertise; each of whom is responsible for making individual decisions; who together hold a common purpose; who meet together to communicate, collaborate and consolidate knowledge from which plans are made, actions determined, and future decisions influenced." (Bloom and Parad, 1976).

3. "An interprofessional team is a small organized group of persons, each trained in different professional disciplines, and possessing unique skills and orientation among whom there is an organized division of labor around a common problem, with each member contributing his/her own talents, with continuous intercommunication, re-examination and evaluation of individual efforts in terms of limitations provided by team goals and objectives, and with group responsibility for the final outcome." (Kane, 1975, page 3).

4. The interdisciplinary team in a hospice draws together and coordinates the planning and work of all persons who have contact with the terminally ill.

These definitions stress the importance of the individual team member's unique knowledge, ability to accept the contributions of other members, and capacity to carry out decisions.

## COMPONENTS OF INTERDISCIPLINARY TEAM WORK

There are six components of team work which must be understood in order to develop an awareness of how a team functions. They are listed below and discussed individually.

1. Role expectations: "Team members maintain a variety of roles which are influenced by internal or external role expectations. Each individual has a set of expectations about how he/she, as well as each other team member, should respond to achieve the stated goals. Professional identity is the conceptualized image a person has of self as a professional, the knowledge and skills acquired from advanced professional education, and the understanding of how these skills can best be applied (Rehr, 1974). Role and function never develop in a vacuum, but are influenced by external role expectations. Any individual is a member of several groups, each with its own set of expectations which influence a person's behavior within the team. Yet studies have shown that there is little congruence

between the way a profession defines its own roles and the way others define them. This is especially true when a higher status profession is delineating roles of a lower status profession. For example, many physicians who automatically consider themselves highest on the status ladder tend to see the nurse as being responsible for implementing medical orders, with little input into other patient care issues. Both internal and external role expectations can lead to role ambiguity (expectations not clearly defined and communicated), role conflict (incompatible or conflictual expectations) and role overload (inability to meet multiple expectations)(Rubin and Beckhard, 1972). These are experienced, according to Festinger, as cognitive dissonance. The central hypotheses of this theory are: (a) the presence of dissonance gives rise to pressures to reduce that dissonance and (b) the strength of that pressure to reduce the dissonance is a function of the magnitude of the existing dissonances (Broga, 1972). In order to function within the team, each member attempts to maintain an equilibrium between his internal values and ideas and the external expectations." (Lowe/Herranen, 1978, p. 325).

2. Decision-Making: In the care of patients and families, decisions are made by individuals alone, by individuals in conjunction with others, or by the team as a group. Thus, the team is one format for problem-solving and decision-making.

   Many types of decision-making mechanisms, such as decision by default (lack of group response), unilateral (authority rule), majority vote, consensus, or unanimity, are utilized by the team. What mechanism is appropriate in various situations will depend on the goal/task to be addressed, the communication patterns, and the leadership style.

   A wide diversity of knowledge and skills is represented in the health care team. Consequently, decisions can seldom be made appropriately in a unilateral or routine manner. Information needed to make and implement decisions requires input from a variety of team members. Research has shown that team members are most likely to support what they help to create. Thus, decisions which can be owned by the team group (and individual members) are most effective.

   Key considerations in the decision-making process are: a) Who has the information necessary to make decisions?, b) Who needs to be consulted before certain decisions get made?, and c) Who needs to be informed of a decision after is it made?

3. Leadership: In any group there are members who will exercise leadership in addition to the designated formal leader. The concept of rotating leadership to the person best qualified to help the team achieve the stated task is being utilized more frequently. "Influence, communication frequency, and leadership should be determined by the nature of the problem to be solved, and not by hierarchical position, educational background or social status." (Rubin, 1972, p. 327).

To be a successful leader an individual must understand both human behavior and the task to be accomplished. They must possess the interpersonal skills to assist the team group in working together towards a specified outcome. The style of leadership depends on the individual's perception of self, professional identity, and group process. Below are several forms of leadership commonly seen in team groups.

a. Authoritarian: In this form of leadership an individual uses their position on the team as a legitimate basis for controlling and directing the group's function. For example, a physician may control the group by limiting the exchange of information, and by requiring unanimous decisions.

b. Democratic: This type of leadership encourages equal participation of all team members. Expression of both positive and negative feelings is allowed. The team's decision-making process may be prolonged as all members may feel compelled to discuss their points of view.

c. Oligarchical: Leadership in this form is in the domain of a selected few. Decision-making under this form often takes place, not in the team meeting, but in a separate meeting of the few.

4. Communication: In all its forms, written/unwritten, formal/informal, communication is the key to the accomplishment of the goals/tasks of the team. To work together effectively team members must share information. How information is acquired, shared, and utilized depends on the patterns of communication. For example, does communication follow formal lines of authority and status where roles talk to roles or is communication based on openness and mutual trust between all members. Optimal team functioning requires that communications be mutual, clear, concise, and a two-way process.

   Questions to be considered are: 1) What are the communication patterns of the team? 2) Who talks to whom? 3) Who is silent? 4) Do team members communicate outside team meetings? 5) Is an effort made to communicate decisions to patients and families?

5. Group norms: These are unwritten rules that govern team behavior. Norms define what is good/bad, acceptable/unacceptable, right/wrong, etc. They also influence leadership, decision-making and communication. It is important for team members to understand how norms were arrived at and how they are enforced. Questions to consider are: Is conflict dealt with openly or avoided? Are certain subjects forbidden for discussion? Are only positive feelings expressed? Do all members participate in team meetings?

6. Goals/tasks: These are the raison d'etre of the interdisciplinary team. "The goals/tasks of the team are thus based on its purpose. Several questions are raised in relation to this: How are goals

defined? Who sets them? How much agreement or disagreement is there among members concerning goals? How much commitment? It is easier for an individual to determine his/her goals than for a group as a team to come to a consensus." (Lowe/Herranen, 1978, p. 324).

## TEAM AS A SMALL GROUP

Although participation in groups is part of our everyday experience, we seldom observe or analyze what happens in these groups, i.e., how decisions are made or why individual members behave in certain ways. All groups have potentially observable patterns of group process. Thus, by becoming aware of the team's group process, individuals are able to enhance their capabilities as observers, participants, and leaders.

The literature on interdisciplinary team discusses several issues and/or components which must be considered in relation to the team as a small group. (Kane, 1975, Borga, 1972; Rubin, 1972). The issues of role expectations, decision-making, leadership, communication, group norms and goals/tasks were discussed in the previous topic. The following are additional issues which must also be looked at in evaluating the team as a group.

1. The individual in the group: As Kane (1975) notes, team members are first individuals, then professionals and then members of an interprofessional team. The individual brings to the group his/her own life experience, values and perceptions of self as a member of a profession. Further, the individual acts accordingly to roles defined by membership in other groups. Thus, individual behavior in a team is a direct result of multiple factors which can be analyzed as part of the group dynamics.

2. Team size: Research has shown that the ideal team size is 6-7 full-time members. This permits the expression of conflicting views as well as participation by all members. In larger groups, the interactions are more formal and controlled, unresolved differences are more acceptable, and subgroups are more common. The size of the team group should be determined by the goal/task to be addressed and should include all professions relevant for the resolution of the problem.

3. Equality: Many writers note that the team should be a group of equals where status differences are minimized. This is an ideal rather than a reality. Struggles around the issues of equality, power, control, and influence are of primary concern to participants at different stages of the group's development.

Another important concept related to the team's group process as discussed by Bion (1959) is regression. He postulates three modes of group regression. They are:

1. Fight-Flight: This consists of either insistent angry confrontative

interactions, or tuning out, fantasy and daydreaming. The fight mode hinders team work when attacks are directed against specific group members or when one's own hostility gets projected to others. Team work is facilitated by the fight mode when open expression of conflict is encouraged and managed. The team's group process is hindered by the flight mode when members withdraw from active participation or use diversionary tactics. The flight mode can enhance the team's work by allowing for introspection to facilitate new approaches to goals/tasks.

2. Pairing: This mode is characterized by expressions of support and intimacy towards another team member or the total group. Pairing hinders the group's functioning by preventing expression of conflict inherent in team work or by the development of antagonistic subgroups. The group's function can be enhanced when pairing allows for a supportive non-threatening environment.

3. Dependency: In this mode the appeal for the group is for support and direction. There is over reliance on the leader or outside authority as well as on rules and regulations. Expressions of weakness, helplessness and inadequacy become the focus for the group's interactions with the goal/task being ignored. Dependency hinders team work when it prevents a member or the group from learning how to manage independently. Dependency also interferes with the team's work when it prevents the group from taking a risk or confronting uncomfortable feelings. Dependency can facilitate the team's group functioning when it temporarily allows the individual member or group to take risks and move towards independence.

The interdisciplinary team as a group needs to preserve its autonomy and integrity in relating to its environment. Awareness of group process as it relates to the team's functioning enables members to diagnose group problems early, to manage them effectively, and to enhance the group's ability to function together successfully.

## COMPOSITION OF A HOSPICE CARE TEAM: KNOWLEDGE AND ROLES

Exercise 3: Knowledge and Roles of Team Members

Purpose: To elicit from each participant, knowledge of the roles and responsibilities of other team members.

Instructions:

1. You will be asked to write on posted sheets of paper one role/responsibility of the following team members: a) nurse, b) physician, c) social worker, d) chaplain, e) pharmacist f) psychiatrist, g) nutritionist, h) volunteer, i) patient, and j) family
2. Following completion of instruction 1, review the posted sheets of paper to delineate role overlaps, and the knowledge base required for each discipline to fulfill roles/responsibilities.
3. Discussion of material will follow.

The complexities that make the existence of the interdisciplinary team necessary also contribute to role overlap, and thus make conflict inevitable. The source of both the greatest strength and the greatest vulnerability to the life and the work of the team is conflict and its management. In order to work together successfully as a team, member's role boundaries must be differentiated yet at the same time remain fluid and flexible. This can only happen when there exists a clear understanding and internalization of one's role. Confidence in one's own professional capabilities is essential to successful negotiation of role overlap.

Tensions between professional viewpoints either undermine the team's efforts at successful conflict resolution or maintain team harmony and stability by denying the existence of conflict. Further, conflict may be attractive and challenging to some team members making conflict the central focus rather than part of the team's natural process to be dealt with. Resolving conflict and role overlap is an important aspect of working together in order to prevent role diffusion and team dysfunction. Flexibility, a sense of humor, and resiliency in the face of conflict assist positively in its management.

## ENVIRONMENTAL IMPACT ON TEAM FUNCTIONING

The hospice environment and philosophy of care emphasize the total well-being of the terminally ill patient and their family unit. Different locations, such as the patient's home, hospital unit, or separate hospice institution, may constitute the care environment. Each of these settings makes demands on the team which should be understood for team work to proceed. For example, the patient's home community may have difficulty in dealing with the dying individual, and may pressure the homecare team to hospitalize the patient when it may not be advisable. Second, the climate of an acute care hospital setting may contradict the priorities set by the hospice team causing unnecessary conflict and stress for both the team and the patient/family. Third, administrative and fiscal constraints impede the implementation of the hospice philosophy, and force the team to accommodate limited resources.

Questions to consider are: What constitutes the working environment of the team? How does this environment influence the team's functioning? How do policies and procedures become established, and how do these relate to the team's functioning? What environmental support systems are available to the team?

## PATIENT AND FAMILY AS TEAM MEMBERS:

The trend in health care towards greater participation of the patient/family as team members necessitates the development of an appreciation of their unique input. The nature of their participation is different from other team members in that the patient/family contribute from their own life experience and response to illness, information pertinent to planning and implementing their care. Research has shown that the patient/family are more likely to adhere to and support the treatment regimen when they are involved in the management of their care and are invested in achieving goals/tasks. (Hayes-Bautista, 1976; Hertz, 1976).

Questions for caregivers to ponder are: What is the most effective way of including patients and families in planning their care? Who acts as advocate for the patient/family? What impact does patient/family participation as team members have on team functioning?

## CONCLUSION TO SECTION 1

### Exercise 4: Analysis of Working Together as a Team

Purpose: To give participants an opportunity to experience what goes into team work by participation in a small group.

Instructions:

1. Large group will be divided into two smaller groups. Each group will have a trainer and an observer.

2. The small group task is to choose three value dilemmas confronting the nurse in hospice care. (Value dilemmas occur when there is a conflict or tension between different ethical principles: For example, prolonging life at all costs when there is no hope for recovery vs. allowing a patient to die, or sharing patient information in team meetings vs. the patient's right to confidentiality. How

team members approach these issues is a function of their individual background, beliefs, and hopes.)

The information given in this section of Module VIII constitutes what is operationally defined as an interdisciplinary team. It is each team's responsibility to establish its own frame of reference and its own style of working together. The next exercise will provide trainees with opportunities to experience and utilize the theoretical material discussed above.

## SECTION II: BECOMING A TEAM MEMBER

The following exercises will be utilized at the discretion of the instructor as learning experiences for Module VIII. Exercise 5 is designed to be utilized when there is a time break between Section I and Section II. The exercise is to be completed by participants back in their work setting and will be utilized for discussion when they return for the final portion of Module VIII.

Optional Exercise 5 is designed to be used in conjunction with the practicum visit to an interdisciplinary team meeting within a hospice program.

### Exercise 5: Interdisciplinary Log

Purpose: To increase participants' awareness of how they communicate and interact with other team members.

Instructions:

1. During the next two days the participant will record on the attached log (Exhibit VIII B) all interdisciplinary contacts they participate in. A minimum of five and a maximum of 10 interactions/contacts should be recorded.
2. Study the log to see if a particular pattern of interaction and communication emerges.
3. These logs will be utilized for discussion.

### Optional Exercise 5: Review of Interdisciplinary Team Meeting

Purpose: To increase the participants' understanding of interdisciplinary team roles and group behavior that can be observed in a team setting.

Instructions:

1. During your site visit to the hospice interdisciplinary team meeting, complete the Review of Interdisciplinary Team Meeting (Exhibit VIII C).
2. Review the completed form. How do the roles you observed differ from the role definitions within the program in which you are currently working?

Exhibit VIII-B

## INTERDISCIPLINARY LOG

| Form of contact (i.e., telephone, in person, etc.) | Where contact took place, (i.e., in hallway, nurse's station, etc.) | Who initiated contact | Reasons for contact | Outcome of contact | Describe briefly your own reactions, feelings, and behavior in interaction |
|---|---|---|---|---|---|
| | | | | | |

Exhibit VIII-C

## REVIEW OF INTERDISCIPLINARY TEAM MEETING

### OBSERVATION NOTES

1. What team members participated in the meeting?

2. What members were absent?

3. Did you note any confusion of role responsibilities?

4. In what areas did you observe role overlap?

5. Describe any notable areas of conflict or cooperation that you observed?

6. Who were the formal and informal leaders?

7. From your brief observations, would you say the leadership style is authoritarian, democratic, or oligarchical?

8. Did you notice any unwritten rules that governed the team's behavior in the meeting?

9. To what extent were the patient/family or the concerns of the patient family involved in the meeting?

10. How did the team meeting compare to those in your current program?

Individual and group behavior can both enhance and hinder the work of the team. The following are examples of:

1. Individual Behavior to Facilitate Achievement of Goals/Tasks

   - Identifing tasks
   - Seeking information from and communicating with others
   - Proposing solutions based on one's own expertise
   - Initiating activity
   - Suggesting new ideas
   - Ability to compromise
   - Assuming leadership role when appropriate by coordinating and summarizing tasks to be addressed
   - Assessing individual responsibility for outcome
   - Providing trust and support to facilitate team's ability to do its work

2. Team Building and Group Maintenance Behaviors to Facilitate Achievement of Goals/Tasks

   - Encourage and solicit participation of others
   - Decide if issues are to be dealt with by total group, subgroups, or individual members
   - Assign and agree to priorities of goals/tasks
   - Contribute to maintenance of task centeredness by appropriate participation and interventions threatening team productivity
   - Assess team responsibility for outcome
   - Evaluate team's efficiency and effectiveness in reaching stated goals/tasks
   - Examine how team interfaces with larger environment
   - Continue assessment of team's internal structure and process

By evaluating and assessing in an on-going way individual and group behaviors, the team will be better able to maintain its equilibrium through awareness of those actions which are functional and dysfunctional to productivity.

## Exercise 5: Analysis of the Team

Purpose: To analyze from the participant's point of view the team they are part of.

Instructions:

1. Utilizing the model outlined by Lowe/Herranen (Exhibit III-D), select the stage that most closely approximates where your team is, and give your reasons for the choice.

Exhibit VIII-D

## LOWE/HERRANEN TEAM DEVELOPMENT PROCESS MODEL*

| STAGE | OBSERVED BEHAVIOR | EMOTIONS | PRODUCTIVITY | |
|---|---|---|---|---|
| | | | INDIVIDUAL | TEAM |
| I. Becoming Acquainted | Polite, Impersonal | Repressed, Neutralized<br>Minimal Conflict | Varied to High | Low |
| II. Trial and Error | Parallel play<br>Pairing<br>Role ambiguity resulting in overlapping of responsibilities | Suspicion, Frustration and Uncertainty | Varied | Low |
| III. Collective Indecision | Pseudo consensus<br>"Scapegoating" | Covert anger, poor team morale | Low | Low |
| IV. Crisis | Confrontation<br>Conflict<br>Delineation of roles/responsibilities | Guilt, open anger<br>Depression | Low | Low |
| V. Resolution/Evaluation | Open communication<br>Shared responsibility with accountability | Satisfaction | High | High |

* From Lowe an[illegible]erranen, 1978, "Conflict in Team Work: Understanding Roles and Relationships."

## CONCLUSIONS TO SECTION II

In order to participate effectively in team work individuals must be aware of 1) what it takes to do the work, 2) what is necessary to strengthen the team, and 3) how to effect individual and team accountability. Open acknowledgement of individual, professional, and team standards are inherent in the concept of accountability. Team members should ask frequently what if anything has become sacrificed in order to hold the team together and/or to protect if from internal/external threats. It must also be remembered that the attractions of team work may obscure the issue of individual responsibility and accountability: every problem in patient care is not necessarily one that requires the attention of the entire team. Many problems/tasks can be resolved by one or two individuals who then can communicate solutions and outcomes to the larger team.

Further, another area of concern for working together is the existence of support both within and outside the team.

> "People whose emotional resources are continuously drained through contact with grief and dying, without being adequately replenished, will not long be able to take proper care of dying persons or to sustain the burdens of staff team work. Support, however, is more than emotional support from team members. It also involves the understanding and the awareness of the community, especially those who contribute time, money, and interest.... Those planning a hospice organization must have built-in support, not merely financial, for team work, so that in principle at least, every one involved with the hospice assumes some responsibility for reinforcing the team concept and helping with the enabling function." (Rossman, 1979, p. 200).

## SUMMARY OF INTERDISCIPLINARY TEAM WORK:

## MANAGEMENT OF INTERDEPENDENCE

Underlying the team approach is the concept that no individual possesses all the expertise necessary for the care of patients and families. In an interdisciplinary team the provision of total care involves the participation and co-ordination of a variety of personnel with different resources and skills all working together towards a common task. Being a team member requires an understanding of the interrelatedness of roles and functions, and the ability to break down interprofessional rivalries. Communication is the essential ingredient in the team approach requiring time, effort and commitment. Thus, in working together the team must manage its interdependence through the cultivation of shared values, team skills, and a common philosophy that transcends the individual's profession.

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# THE HAZARDS OF TEAMWORK

Quentin Rae-Grant

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# THE HAZARDS OF TEAMWORK

Dare we today question the value of teamwork? By now it holds a sacred position in American mythology, somewhat uncomfortably situated alongside rugged individualism. Its attractions increase as team efforts are woven into the fabric of our society in multiplying areas of endeavor--and as rationales are found for these efforts in the problems raised by specialization, by shortages of trained manpower, by apparent administrative necessities, by the scope and complexity of the tasks at hand. Nowhere is this trend better illustrated than in the mental health profession.

Teamwork, according to Webster, occurs when "a number of associates all subordinate personal prominence to the efficiency of the whole." Even though we all know this is rarely what happens on teams, the team idea may remain too seductive to resist. Our moral condemnation of aspirations toward *personal prominence* may interfere with our evaluation of the effectiveness of *personal efforts*; and we may fail to distinguish between Webster's *efficiency* of the whole and the actual *effectiveness* of the whole. It is difficult for any one publicly to resist supporting a system that intends to squelch prima donnas and grandstand plays. No one reveres pigheaded loners or wants to be perceived as one; besides, both the pooling of credit and the parceling out of blame appeal as much to self-interest as to altruism.

Most professional persons know they have been helped and have helped others through collaboration both within and among different disciplines, but they may too readily be persuaded that a formally constituted team is needed to perpetuate or promote such collaboration. They may presume that a team somehow guarantees the productivity of such interchanges, promising general improvement in colleagues' professional performance. In fact, magical expectations notwithstanding, team formation and team spirit are as likely to result in a leveling down as in a leveling up, and this hazard is maximized by uncritical overvaluation.

Some of the arguments in favor of teams betray their pitfalls and perhaps their origins. The slogan "shared responsibility," as an example, seems to promise that each patient will be better off because more people are taking responsibility for his care. To be sure, two heads may be better than one, but quantity is no assurance of quality. The myth that the total team is effectively discharging responsibility for a given patient may mask the fact that no one fully accepts responsibility or feels himself to be ultimately accountable for what happens. A team may engage in a covert conspiracy to carry on subtle forms of reciprocal alibiing and circular buckpassing, especially passing the emotional buck nonstop around a circuit with no end; and the omnipresence of consensual validation may only serve to oblige no group member to think a problem through to resolution. Further, some individuals may find in the anonymity of team membership, tacit permission to behave in less responsible ways than if the only appraisal available to them were self-appraisal.

Even a team of strong individual "parts," each with major contributions to make, may be a weak team as a whole, and this paradox may exist not only where teamwork fails but where it succeeds, and not only despite teamwork but because of it. If egalitarian teamwork brings about sufficient blurring of roles and if jobs are sufficiently undifferentiated, the full thrust of each member's clinical effectiveness is never felt. Diffused identities and diffused social structure breed inefficiency and create adventitious anxiety that interferes with and undermines therapeutic work. Many teams have already experienced this discouraging vitiation, especially where their egalitarianism has a spurious quality.

Unfortunately, the alternative way to play the team game is equally treacherous. The over-differentiation of roles and the artifical scotomatization of areas of competence restricts individuals' effective functioning and cramps their style. Further, inappropriate specialization may lead to gratuitous distortions of clinical material. Having a member of one discipline evaluate a child while a member of another evaluates his parents may make for good teamwork, but one might question whether it makes good sense. It magnifies the tendency to champion one generation "against" the other and may create a situation not unlike the blind men and the elephant.

The trouble is that it is difficult to keep one's balance, walking the tightrope between over- and under-differentiation in the structuring of a team and the functioning of its members, and a precarious standstill may result.

In addition, despite claims of efficiency, coordinating a team eats up its members' time in itself; and, still more disabling, the team organization drains its members' energy. It may exhaust sources of emotional involvement that might better flow toward persons the team seeks to help. For, to the extent that the team yields to the temptation to become an end in itself rather than a means to a therapeutic end--to the extent that teamwork becomes a preoccupation rather than an occupation--each team member's commitment to his team will infringe on his commitment to his patients.

Clinical teamwork, however, has been extolled not only because of its alleged direct benefit to patients. The sharing of responsibility that the joint approach promotes has also been defended as a way "to minimize counter-hostility and defensiveness" on the part of personnel--that is, as a valiant attempt to replace countertransference to patients with transference to teammates, to shift the arena for conflict away from the therapist and his patient into the field of the group dynamics of the team.

There is nothing necessarily wrong with deriving support from colleagues, nothing wrong with seeking to be complemented or even complimented; but there is a great deal profoundly wrong with colleagues agreeing mutually to utilize each other to avoid coping honestly with the feelings their patients engender in them. That, in essence, is a cheap defensive trick which shortchanges all concerned and which most helpers would strongly discourage in those they were trying to help. The very backbone of all clinical work and the most crucially significant challenge our professions afford is the sobering challenge of honestly facing oneself by oneself. Unless we are willing to expect less than this of our patients, we dare not allow the teamwork dodge to lead us to expect less than this of ourselves. We dare not permit this cardinal abuse of teamwork to facilitate evasion of this challenge.

Teams, like institutions, may provide a protective mantle for their members to hide under, reducing the likelihood of direct interaction or communication with patients, who become increasingly isolated in the Kafkaesque process. Especially when what has to be communicated is an administrative decision by which a patient (or his parents) will be antagonized or a diagnostic fact that will be painful to accept, a therapist may seek comfort by summoning authoritative support from other professionals. Then we hear it argued that, through such a joint approach, the patient will be more easily and quickly convinced of the reality or necessity he may wish to deny or protest against. We even hear that such a patient is helped by such coalitions to cope with his anger and resentment (deemed the result of projections)--that he is more likely to trust the good intentions and believe the pronouncements of several staff members than just one--and that he is less likely to "take it personally."

No doubt such team tactics "work" and work quickly--as if speed were a virtue--but at a price we should not be willing to pay. At worst they amount to sheer bulldozing. At best they serve to reassure only the team members, while they arouse in the patient the suspicion of a snow job. The implication of the need to amass an array of experts to convince is that no one of them individually would be adequate or could be believed. The devaluation of each leads to the downfall of all. Surely, such ploys convince no one outside the team of good intentions; rather they confirm the presence of doubt and guilt. And certainly they only act to forestall or suppress outrage by diffusing the target at which it might be directed or by simply overwhelming the patient-victim. As to the notion that a patient's paranoidal denial and projection may be effectively dealt with by the multiple impact of a team effort--used at times to impose a consensus, at times to trap a patient into facing the truth by confronting him with witnesses to his own inconsistencies: Does any clinician seriously believe these defenses can be overcome by onslaught or litigenous trickery? Quite the contrary--experience indicates they may well be reinforced.

Sometimes it is advocated that such tasks of persuasion be expedited by a division of labor in which one teammate plays the role of the good guy and another plays the tough. Perhaps the social worker will be a supportive, sensitive friend to soften the blow and the doctor will be the authoritarian enemy, the voice of harsh scientific reality. It is argued that the patient's split allegiances can be manipulated constructively, that he will benefit from the demonstration of an intimate working relationship, that his witnessing candid professional collaboration in solving the "problems" of his--or his child's--case will lend credence to the findings and recommendations he is being asked to accept.

Perhaps. But the manipulating may degenerate into simply hustling the patient between bribery and blackmail, and the problem-solving may strike the patient as either phony or bewildering. Indeed, the whole strategy risks jeopardizing the patient's faith in the competence and integrity of the persons seeking to help him. To expect patients to be swayed by such essentially dishonest play-acting is to take a very patronizing and degrading view of their sensibilities and general awareness; and to suggest, as some do, that such a division of labor within a team is not a dishonest act, because social workers and psychiatrists actually fit these type cast roles, is to insult and discredit both of these professions most inappropriately. Yet one hears this stand defended, probably as a poor compromise, designed to resolve some petty rivalries and salvage some status for these respective professions by claiming for one a monopoly on knowledge at the expense of being able to feel and for the other a monopoly on sensitivity at the expense of being able to think. Most patients can recognize such thinly rationalized exercises in oneups-manship.

The ultimate argument offered to defend the conjoint acting out of a dichotomy between the firm-directive and the gentle-understanding attitude is that no one person could embody both, if the situation required it. If that is a message we can contemplate conveying to our patients, we should throw in the mental health sponge.

These arguments seem to rationalize serious misuses of "therapeutic" teamwork in which facile gamesmanship tends to replace honest confrontation and the competent discharging of difficult duties. They also illustrate a more general hazard of teamwork--a hazard of team spirit. Team spirit connotes a will to win. It thrives in a context of rivalry and when a common enemy is perceived. Typically, the team ethos gravitates away from the "alliance for" idea and toward the notion of a "war against"; and, typically too, though the enemy on whom war is initially declared may be an abstract demon often enough, the enemy against whom war is waged shows a tendency to materialize. Both of these trends endanger clinical work: To the extent that a teammate is tempted to see his patient as a transient embodiment of an abstract evil on which his team has declared a holy war, it becomes difficult for him to pay close attention to his patient as an individual, and therapy suffers; and, to the extent that team strategies, such as those described above, bespeak somewhat militaristic conceptions of a team as a group intent on winning and of a patient as someone to be outsmarted, outclassed, and, eventually, defeated (for his own good, needless to say)....to this extent these strategies illustrate how serious a threat to clinical work team spirit may become. For, in such work, to "win" is, in the long run, to lose.

But the fact that some professionals feel a need for these specific forms of "therapeutic" teamwork has an alarming implication quite aside from these hazards of team spirit. It implies a serious underestimation of the potential capabilities of the individual therapist and of the therapeutic possibilities of intimate and confidential, on-to-one clinical work. Both of these misjudgments threaten to corrupt what is still the most valuable therapeutic tool we have. If we begin to expect that an individual therapist cannot shoulder total responsibility for a case and carry out genuinely difficult clinical tasks authoritatively on his own, we will begin to meet these expectations. The resulting downgrading of independent work would hurt any profession or any team or organization, but the loss in the mental health field would be uniquely crippling because of the very special and irreplaceable contribution such work offers in clinical pursuits. Predictably, in such a malignant degenerative process, efforts would be made to minimize this loss by a retrospective devaluation of what committed, competent, confident clinicians have traditionally accomplished *alone*. Alarmingly, just such rationalization is already evident in some quarters.

At this historical juncture we may have many a team the sum of whose members' individual effectiveness is greater than their collective effectiveness. But, if our standards slip sufficiently, we will disastrously "correct" this situation by diminishing the potency of the individual members themselves. If we carry on training in an atmosphere in which the consensus expresses doubt that a trainee can withstand anxiety and failure on his own, we will train a generation of clinicians who do not develop their personal talents or realize their potentials and who lack confidence in their ability to go it alone and continue to learn independently. Through training in teamwork we may guarantee that no trainee will ever be left all to his own devices, that he will never be urgently forced to face his own feelings and inadequacies on the spot with no place to hide and no one to hide with or behind. That is, we may manage systematically to deprive trainees of the only experience from which a solid sense of independent competence can come, the experience of shouldering total responsibility and mastering with insight the anxieties this burden must generate. In doing so, we would ensure that their careers as teammates of the future would be retreated into from a position of weakness and need, rather than chosen from a position of strength. The impact of this vicious circle on the teamwork of the future is appallingly clear: hazards already existing will be maximized.

We would be the last to recommend that teamwork be taken off the remedy market, never to be prescribed again. Neither do we wish to label it a poison to all systems. At times it is the agent of choice--even life saving. Still, it must not be advertised as a panacea, and the consumer must be alerted to its untoward, debilitating and potentially lethal side effects. Its prolonged usage, in particular, may lead to irreversible changes and may be addicting. There is no built-in, foolproof guarantee that is will cure all ills in any dosage or that it will even effect improvement in every case. Lest we overestimate the potency of teamwork and set ourselves up for a painful disillusionment, we should be aware too that its attrative packaging, the term "team" itself, has a certain placebo effect which may account for some of its initial action as a tonic. Teamwork, in summary, need not be toxic; but it is no "miracle drug" either.
*Caveat emptor*.

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# MODULE IX: ETHICAL AND LEGAL ISSUES IN THE CARE OF THE TERMINALLY ILL

PARTICIPANT MANUAL

DEVELOPED BY:

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# MODULE IX: ETHICAL AND LEGAL ISSUES IN THE CARE OF THE TERMINALLY ILL

## Purpose

The purpose of this module is to describe ethical and legal issues and dilemmas confronting the nurse who cares for the terminally ill or dying patient and family. Use of a framework for clarifying and reflecting on ethical issues and dilemmas will be demonstrated.

## Contents

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|---|---|
| Overview of module and introduction to ethical and legal aspects of hospice nursing | 20 minutes |
| Lecture/Discussion: description of framework for analysis of ethical issues and dilemmas | 45 minutes |
| Lecture/Discussion: demonstration of framework with case study | 35 minutes |
| Small group discussion with facilitator and recorder: discussion of case studies using framework | 55 minutes |
| Summary of small group discussions | 15 minutes |
| Summary of Module IX | 10 minutes |

Total Time: 3 Hours

## Objectives

At the conclusion of Module IX participants will be able to:

1. Identify ethical issues and dilemmas characteristic of hospice nursing
2. Identify legal aspects of hospice nursing
3. Distinguish ethical and legal aspects from technical aspects of hospice nursing
4. Identify selected ethical approaches which can be used to reflect on ethical issues and dilemmas in hospice nursing
5. Use a framework for analyzing and making decisions in situations

of ethical conflict in hospice nursing

6. Describe models for ethical relationships of nurses/patients/ families and nurses/other health professionals in hospice nursing

7. Identify constraints and challenges to ethical practice in nursing settings

## RESOURCE MATERIALS: CONSIDERATION OF ETHICAL AND LEGAL ISSUES IN THE CARE OF THE TERMINALLY ILL

### Overview

Caring for the terminally ill and dying raises many ethical and legal concerns. Even though the team concept is emphasized in caring for the terminally ill, the hospice nurse is in a particularly critical position and is frequently confronted with such dilemmas. Nurses frequently hear such questions and concerns as the following:

> To the hospice nurse in a home setting, the patient asks: "Is it really cancer? Why am I not getting better?" The daughter-in-law asks: "Should I be taking care of my mother-in-law here at home when it takes so much time away from my children? It would be easier if she were in the hospital."
>
> To the nurse in a palliative care setting, the patient says "I'm ready to die. Can't you hurry it up?"

These questions and concerns involve ethical and legal as well as technical dimensions. The differences between these dimensions is very important in caring for the terminally ill.

Ethics is a branch of philosophy which systematically examines questions of what is "right" and "good". Ethics is concerned with both the general nature of morals/ethics and moral values and the specific moral choices to be made by an individual. In health care, one confronts issues of applied ethics in situations where there are conflicts about the right decision or action to take. One is often concerned with how to justify to oneself and others a decision to take a particular course of action. The questions above are in the area of applied ethics. While studying ethics does not give us specific answers to resolve particular conflicts, it can assist us:

- To clarify and refine issues and dilemmas
- To help make more reflective decisions rather than simply reactive ones
- To provide the language and framework with which to talk about and discuss issues and their ethical, legal and technical aspects with

colleagues, patients and their families

## Distinguishing the Legal, Ethical, and Technical Realms

Situations in which the ethical aspects are in the forefront as distinguished from the legal and technical aspects include:

- When the nurse, other health provider or patient is faced with a conflict between individual human needs and the welfare of others and situations in which there are alternative choices available for decision and action which often seem equally unattractive
- When caregiving choices should be guided by ethical principles containing a theory of justification
- When choices are made rationally
- The choice is effected by the feelings and values of the individual which in turn are affected by the particular demands of the situation

  Examples include issues of self-determination such as the right to reject treatment, the most just way of allocating scarce resources and rights of conscience of health care personnel. This is a different realm than the technical where, for example, decisions might be related to choices of a sleeping medication to achieve certain effects, methods to prevent decubiti, or the safest way to ambulate a particular patient. These are generally questions with solutions based on empirical knowledge.

To distinguish the legal from the ethical, one looks to law as a system of principles and processes by which people in a given society deal with disputes and problems without resorting to force. One thinks of legal decisions made in the courts and government legislation which are implemented through rules and regulations. Examples include: the Supreme Court decision on abortion, legislation on "living wills" in some states which give individuals the right to reject certain treatments, the Quinlan decision in New Jersey, and nurse practice acts which tell the public what they can expect from the nursing profession in terms of duties and obligations.

While a particular course of action may be legal, it does not necessarily follow that it is ethical. For example, if one lives in a state where the "living will" is legal, it does not say that one should have such a document only that one is permitted to have certain actions carried out on one's behalf. One must still struggle with the decision of whether or not it is "right" or "good" to sign a "living will" for one's self or to assist another person in thinking through such a decision. While the nurse has an obligation to find out whether a law exists which applies in a given situation, there are many situations for which there are no specific laws, for example when an individual requests being allowed to die, when the nurse decides whether or not to tell the truth to a patient, or, when a conflict of patient/family/provider values arises.

As a nurse, you may immediately respond, when confronted with an ethical decision, by consulting the ANA Code for Nurses with Interpretive Statements. This document is useful in terms of general guidelines for the individual nurse and the profession, but it does not, for example, tell the nurse caring for an individual who is terminally ill what to do when pain control becomes an issue or when the individual protests a particular treatment that causes a great deal of discomfort when the nurse "knows" that it is in the patient's best interests. These are ethical issues which require a systematic and reflective thinking process based on ethical inquiry.

A variety of issues with ethical and legal dimensions can be identified in caring for the terminally ill:

- Treatment versus non-treatment
- Research protocols
- Admission policies
- Euthanasia and suicide
- Roles and relationships of various team members
- Definitions of death
- Means of pain control

Examples of specific ethical concerns in these issues are:

- Self-determination and the informed consent process

- "Rights" of all involved in a particular situation
- Whether or not coercion is to be used to achieve certain ends
- Identification of relevant moral principles and responsibility for particular decisions and actions

Any of these concerns frequently arise for the nurse in particular patient care situations and relationships.

## Team Relationships

The relationships of providers, patients and families underlie whether and how many of these ethical concerns are considered and resolved. Veatch, a philosopher, suggests that there are four models for the physician/patient relationship which have implications for all relationships on the health care team. They have special significance for the nurse who is frequently at the point of interface between the physician and patient/family or the institution and patient/family. (See the Murphy and Jameton articles in the Appendix for more detailed discussion of the moral situation of the nurse.) The nurse's situation is particularly sensitive in light of his/her role as an employee and the nurse's multiple sources of accountability to:

- The patient
- One's self
- The employer
- The profession
- The state

These sources of accountability often conflict. The position of the nurse in-the-middle also affects how the nurse works with ethical issues and dilemmas in light of the actual or perceived risks in doing so. Raising ethical and legal issues and concerns to the conscious level often challenges present practices generally in health care and specifically in care of the terminally ill. The relationship models suggested by Veatch are:

- Engineering
- Priestly

- Contractual
- Collegial

The engineering model implies a relationship wherein the provider simply presents all the facts to the patient and the patient decides what should be done. The nurse or physician carry out the patient's wishes with no consideration of their goals and values. The focus of decision making is on the patient. This has the potential for being a morally outrageous situation for the integrity of the health professional. Nurses need to be aware of this implication when they support the nurse's role as advocate without examination of the concept.

At the other end of the continuum is the priestly relationship. Here the professional decides what is in the patient's best interests, the patient's values are not considered and a more paternalistic relationship is established. This model tends to transfer expertise in the technical, professional area to the moral realm. An example is the case of the nurse stating to the patient, "Speaking as a nurse, I think that you should participate in this research, possibly for your own benefit, and for the benefit of others who may have your illness in the future." This kind of relationship threatens the patient's autonomy and self-determination.

The collegial model suggests a relationship in which health professionals and patients are like colleagues who share common goals and status equality. Decisions are reached through a consensus. This is probably an unrealistic view in light of the frequent ethnic, value, class, educational and economic differences between professionals and patients/families. This model has implications needing specific discussion and consideration by professional members of the team caring for the terminally ill particularly considering the typical authoritarian, bureaucratic modes of operation in most health care settings. The authoritarian, bureaucratic model frequently has different ends in view than the care and comfort of the patient which is the goal in care of the terminally ill. The hospice concept of care challenges the hierarchical, authoritarian mode of service.

The contractual model for relationships is a covenantal rather than a legalistic concept. All members of the team, including patients and families, discuss their obligations and the benefits to be obtained through particular decisions. This model recognizes that professionals and patients may have different interests, values and goals, but that decision making on major issues is a shared process. It recognizes the patient's need to maintain control over significant decisions about his/her own life and destiny. The basic value framework for decision making is the patient's own values. Both the patient and the health professional maintain their own moral integrity. Under carefully defined conditions, the contract may not be initiated or may be broken after discussion. The contractual, covenantal relationship may be implicit in the hospice concept of care.

In summary, these relationships, which may be overt or covert in caring for the terminally ill, need to be examined in order to assure that they enhance rather than impede the goals of care and comfort for the terminally ill patient.

The next section will discuss a framework for analyzing ethical dilemmas prior to making decisions. The framework is preceded by general remarks which form a context for the framework.

## INTRODUCTION TO THE FRAMEWORK FOR ANALYSIS OF ETHICAL ISSUES AND DILEMMAS

In caring for the terminally ill, the nurse is frequently confronted with the ethical dimension of relationships and institutional policies. The nurse should also be aware of the legal dimension in the sense that she/he needs to check with legal counsel when in doubt as to whether or not there are federal or state laws or legal decisions applicable to a given situation. (See Yarling's articles in Appendix for more explicit discussion of the professional, legal and moral aspects of telling the truth to a terminally ill patient.) Nurses sometimes assume incorrectly that there are laws which either permit or prohibit a particular course of action and fail to fully explore and seek legal information or advice.

After reading the article "Anatomy of an Ethical Dilemma" and becoming acquainted with the framework for analysis, the framework will be used to look at an illustrative situation in which the nurse is in conflict about the right thing to do. This is not an exhaustive examination of all alternatives and all aspects of decision making, and you will probably think of other aspects as you read and reflect on your own experiences. Thinking about and acting in situations in which the ethical dimension predominates has many ramifications for the individuals in the nurse/patient/family relationship and for the institutional and community systems of which we are all a part.

## The Situation

Mr. C. is a 70 year old former repairman for a telephone company. He is terminally ill with cancer. This is his second admission to the palliative care unit where you are on the nursing staff. According to his wife, he has been taking only fluids for the past two days and has refused to get out of bed, saying that he is too weak. His wife reports to you that he has told her on several occasions that he is going to take something to "put me out of my misery. I'm not any good to you or anyone else." Mr. C. also knows that the "living will" is legal in his state but says he trusts the doctors and nurses to do whatever needs to be done. His wife is quite distraught, but maintains that she does not want you to tell anyone about Mr. C.'s mentioning suicide to her. The C's have two children who are married and concerned about their father's condition. They live out of state but call their mother at least twice a week and visited Mr. C. during his last admission.

This situation brings up the issues of who should make decisions for Mr. C., a verbal request for euthanasia, confidentiality, and "rights" of all concerned when a person is teminally ill.

It is the end of your shift, but you decide to have a cup of coffee and think about your next steps in relation to the framework for analyzing ethical dilemmas which was discussed at your last in-service education meeting. Your own personal feelings are that since Mr. C's pain is well controlled, he has no right to think about suicide. You feel that you want to maintain the confidentiality Mrs. C. requested, but also feel that the team should know that Mr. C. is (according to his wife) talking about suicide. This is an ethical dilemma for you involving conflict and what appear to be equally unattractive alternatives.

First, you think about the questions from the data base: who are all the people involved in Mr. C's care? Primarily, they are Mr. C., his wife, and the palliative care team. Secondarily, Mr. C's children are also involved. You consider some alternatives for action and their possible consequences:

- Discuss the situation further with Mrs. C. and try to convince her that the team or a team member should discuss Mr. C's feelings about his care and future with her and Mr. C.
- Inform Mr. C's personal physician without discussing it with Mrs. C.
- Tell Mrs. C. that you want to discuss this with her and Mr. C. together
- Tell Mrs. C. when you next see her that you can do nothing and she should just "hope for the best." Maybe Mr. C. won't mention it again

Consider the probable outcomes for each of these choices for all involved in the situation. If unsure about the legal ramifications of these alternatives, they could be discussed with the hospital's legal counsel while maintaining confidentiality.

In addition to the data base gathered, you also need to consider who should make decisions for Mr. C., since there may be more than one opinion as to whether the patient has the final determination about what happens to his/her body. In this situation, Mr. C. may be considering his care in terms of the priestly model of the relationship with the palliative care team, while the team is trying to operate within the contractual model which conflicts with the more paternalistic model of professionals making all the decisions for the patient/family.

Remember that in the hospital setting, health professionals are generally viewed as being in positions of authority and power. But, it cannot be automatically concluded that the professionals should make final decisions since they may be acting on values grounded in the traditional medical ethic which says that everything that can be done for the individual should be done without ascertaining the individual's wishes. This is one argument for having different staff in a palliative care unit where care and comfort, rather than cure, are the goals.

You also reflect further on Mr. C's reported request for some form of euthanasia and wonder about the arguments you have seen in the literature for and against active and passive euthanasia and the confusion around these concepts. Simply invoking a quality of life or sanctity of life argument does not resolve the dilemma becuase you also realize that you do not want to impose your own values on Mr. and Mrs. C., and on Mr. C's right to decide what happens to his body. The considerations would change if Mr. C. had been declared incompetent, under a stated set of criteria, to make these decisions. It is morally very difficult, if not impossible, to justify anyone else making decisions for Mr. C. unless this has been done. At this point in time, Mr. C. is still considered to be competent to sign informed consent forms and to make his own decisions.

You think about the criteria for deciding on an alternative in terms of Mr. C.'s medical condition and status. You also consider Mr. C.'s psychological condition and his discouragement about his pain for which he sometimes refuses medication. You also know that the C's financial situation is deteriorating and that the children have large families and do not contribute to the C's finances. You think about nursing's emphasis on the "whole" patient and the proclaimed role of the nurse as patient advocate.

The nurse should also take into account the psychological, social and spiritual dimensions of what Mr. C's illness means to him on both a long-term and a short-term basis. Since protocols have been established for care in the palliative care unit, you do not think about the ordinary versus extraordinary means argument which often surfaces in looking at alternatives for action in traditional hospital settings. Nurses need to be aware that this is not a particularly helpful distinction because what is ordinary in one institution or geographic area may be extraordinary in another institution or area.

In looking at the alternatives, you are also concerned with facilitating the decisions that Mr. and Mrs. C. want, rather than coercing those actions the team desires, which constitutes another ethical consideration. This will become even more significant if Mr. C. continues to talk about taking his own life. If one is commited to the individual's right to self determination in the strict sense, then individuals also have the right to make what others may consider to be tragic choices. Self-determination does not mean however, that individuals then have the right to expect that someone else will help to carry out a choice with tragic consequences. The right to self-determination does not carry with it an automatic obligation for someone else to participate in executing particular choices, should, for example, Mr. C. ask his wife or a nurse to participate in his wish to do away with his life.

Additionally, you would think about the possible alternatives in light of whether they enhanced or negated such principles as self-determination and the principle of nonmalfeasance, that is, doing no harm. This principle also requires that all involved are thoughtful about their actions and consider them in light of professional standards of care. Nurses might consider which alternative best serves the well-being of both Mr. C. and his wife by taking into consideration the ANA Standards of Nursing Practice.

In considering various ethical approaches to the selection of alternatives, the nurse could look at the alternatives from a utilitarian position. She could consider which alternative leads to consequences of the greatest amount of happiness or least amount of unhappiness for the greatest number of people involved with Mr. C. One problem with this utilitarian approach is that the individual patient's wishes may be overruled. The wishes of the larger number of people will override those of the individual if they are in conflict. Recall that this is a more group-oriented ethic which could conceivably be used to justify almost any decision with little consideration of the individual. Although this approach is used in many policy decisions in health care, it conflicts directly with the traditional medical ethic which says that everything that can be done should be done for the individual.

In looking at the alternatives from a deontological approach, a more duty-oriented approach, the nurse would invoke particular ethical principles such as "do no harm" which she would then be willing to universalize in all similar situations. Using this approach in a strict interpretation the nurse would also consider that there is something inherently right or wrong about a given alternative regardless of the consequences. If the nurse uses a principle, such as respect for the individual, the second and fourth options would be ruled out unless they were modified in some way. The "respect for the individual" principle also requires that nurses do not impose their own values on patients and families in making decisions. This is a potential source of stress and tension for the nurse which is modified under the contractual, covenantal relationship where the values of all are taken into consideration in making significant decisions.

Using a rights-based approach, the nurse might make the claim that Mr. C. has a moral, but not necessarily a legal, right to do anything he wishes with his own body. Or she might make the claim that in light of Mrs. C's relationship as Mr. C's spouse, Mrs. C. has both the right and obligation to do all she can to prevent Mr. C. from taking his own life. A principle of sanctity of life would justify this claim. There is some difficulty in using this approach since all the individuals involved may claim rights which conflict with one another. Considering the Patient's Bill of Rights of the American Hospital Association, and the patient/family as the unit of care, the nurse would rule out the second and fourth options.

Please note that it is difficult, ethically, to justify doing nothing or the nurse's making an arbitrary decision to notify Mr. C's physician without discussing this with Mrs. C. further, since Mrs. C. requested that this information be kept confidential.

Identification of the values of those involved, and the underlying values inherent in each of the alternatives, is another aspect to consider before making a decision. For example, the individual nurse who values self-determination for herself as a professional person and for patients will often choose an alternative expressive of this value. Or, the nurse and patient may hold values which reflect the idea that physicians should make all the decisions related to patients. Thus, values influence the ethical approach(s) used by health professionals and patients/families. They also influence the gathering of a data base for ethical reflection and influence how one thinks about the questions of who should make decisions and the criteria to be used in making decisions with and for the terminally ill and dying. The objectives of hospice care, the importance of the control of pain, and the involvement of patients and their families reflect values about the importance of individuals and of living, while dying, in community rather than in isolation.

In this situation, the nurse does have time to reflect on her decisions and actions. This is not always the case, e.g., when a patient arrests in the nurse's presence and a "no code" has been expressed verbally but not put in writing as required by institutional policy.

In summary, this discussion will hopefully provide a point of departure for discussion of any number of ethical dilemmas confronting nurses who care for the terminally ill.

# MODULE IX

## ETHICAL DILEMMA I

You are the nurse in a palliative care unit. Mr. R., a 66 year old former high school teacher is terminally ill with pancreatic cancer and has had several surgical procedures. He has decided that he does not want to participate in the clinical trial of a new chemotherapeutic agent. He told you that he wants to go home to "die." He feels that his pain can be controlled at home as it has been before. He has written a "living will" which has been in his chart since he was told that he did have cancer. He has told you several times that he has a great fear of being kept alive "with all those tubes and a machine, like they did with a friend of mine." His family and physician have assured him that this will not happen to him, but he is not completely convinced and wants to return home. The local hospice has a home care service which Mr. R. can use. Since his wife died two years ago he has been living with his son and daughter-in-law. The daughter-in-law has the primary responsibility for Mr. R's care at home. She also takes care of two preschool grandchildren during the week. One day she waits for you in the hall outside of Mr. R's room and tells you that she does not want the responsibility for caring for him again and wants him to stay in the hospital. She wants you to talk with Mr. R's physician about keeping Mr. R in the hospital but does not want you to tell anyone that she has discussed this with you. You explain to her that this is not your responsibility and that she should discuss it with the physician. She refuses. You also know that one of the hospice volunteers had some concerns about whether Mr. R's care at home was adequate before this last admission. What should you do?

# MODULE IX

## ETHICAL DILEMMA II

You are the nurse in a hospice home care program. Mrs. T. is a 34 year old mother of three school-aged children. Her husband is employeed in middle management in a local industry. She has been very active as a volunteer. She is terminally ill with cancer and has had bilateral radical mastectomies and cobolt therapy. She told you today that she feels like an increasing burden to her family since she can no longer care for her home and children and that she has considered taking her own life but doesn't have the energy to carry it out. She asks if you would help her carry out her wishes when she decides "that the time has come to end it all." She says that she knows her husband is "involved" with someone out of town. Since she's not going to live much longer anyway, she might as well end it sooner rather than later. You do not believe that suicide is ever justified and tell Mrs. T. your opinion. Then you start to wonder about your action and what you should do next.

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# APPENDICES

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Ethical Dilemma I

Ethical Dilemma II

## PARTICIPANT NOTES

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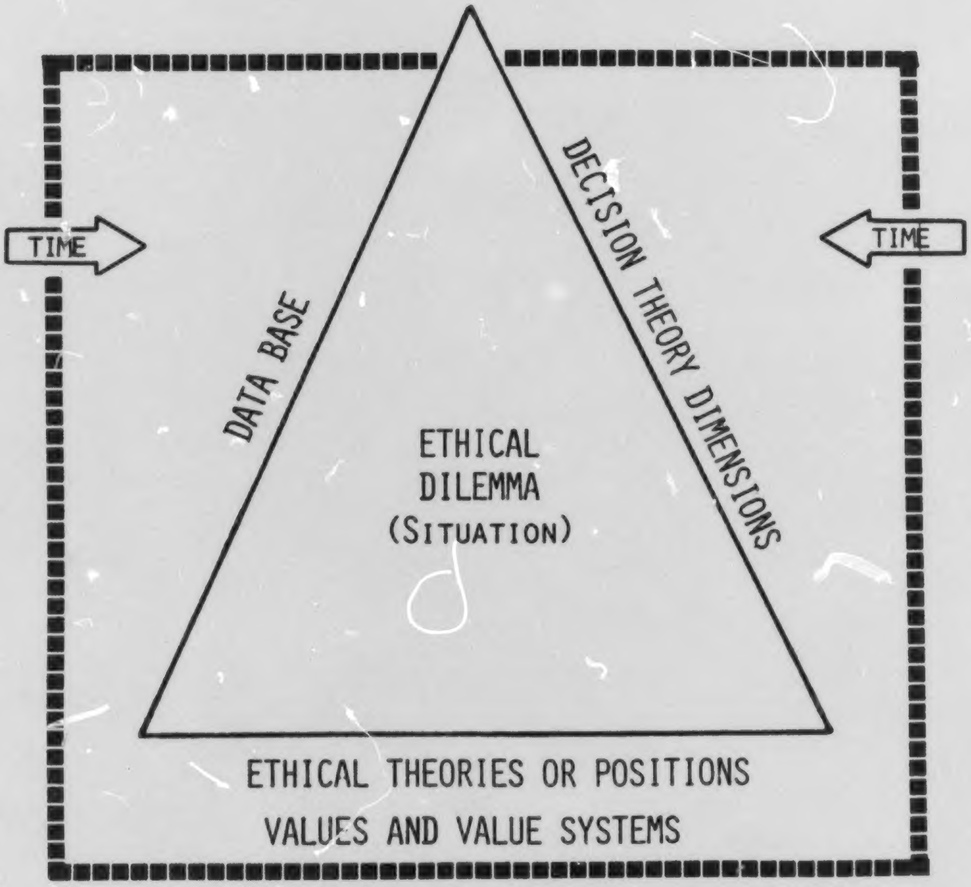
# ANATOMY OF AN ETHICAL DILEMMA: THE THEORY

BY MILA A. AROSKAR


TIME
TIME
DATA BASE
DECISION THEORY DIMENSIONS
ETHICAL DILEMMA (SITUATION)
ETHICAL THEORIES OR POSITIONS
VALUES AND VALUE SYSTEMS

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Examination of the anatomy of ethical dilemmas within health care generally, and specifically in nursing, is an essential first step in the thoughtful consideration of dilemmas. Ethical dilemmas occur both at the nurse-patient-family level of interaction in hospital and home settings and at the policymaking level of institutions and communities.

A dilemma either involves a choice between equally unsatisfactory alternatives or a difficult problem that seems to have no satisfactory solution.

Ethical dilemmas, in general, involve interrelationships in which there are conflicts and tension. Questions arise: What ought I to do? What are the harms and benefits of this decision and action? For whom? Bioethical dilemmas emerge from health care situations in which any answers are far from clear.

Some health workers have equated moral and ethical issues with legal issues and suggest recourse to lawyers to resolve ethical dilemmas. However, there are many limitations in law. Legal decisions often do not provide answers to specific ethical dilemmas confronting health professionals and may create new dilemmas by their very nature.

Ethical dilemmas have always been with us, but their nature in health care settings has changed radically with development of new knowledge and technology. Years ago nursing texts addressed such "ethical" concerns as appropriate behavior between physicians and nurses, respectful wearing of the uniform, and the need for nurses to follow the ethical policies of the hospital. In the 1980s, this does not even touch on the complex ethical dilemmas faced by both individual nurses practicing in bureaucracies and by the nursing profession itself.

Bioethics, as a discipline applying ethical thinking to the health sciences, has developed most rapidly within the last decade. Traditionally, ethics has had to do with individual decisions regarding what should be sought in life and what should be avoided, ways and goals of life, and duties and obligations. Bioethics concerns choices and conflict around such health care issues as longevity versus freedom from pain, full versus partial disclosure of health information, rights of individuals versus rights of society, and rights among individuals in the distribution of limited health care resources.

How does one begin to think about and structure these complex issues which involve so much uncertainty and ambiguity?

## Ethical Theories

Ethical theories and reasoning do not solve ethical dilemmas, but they do suggest ways of structuring and clarifying them. They help us go beyond ethical slogans or one-sentence general principles for justifying decisions and actions, for example: abortion is wrong, period.

To understand how ethical theories structure solutions in ethical dilemmas, we can look at what three positions in ethical reasoning--utilitarianism, egoism, and formalism or deontology--offer in the way of suggested solutions. Each position structures ethical dilemmas in particular ways.

Utilitarianism. At the present time, the utilitarian position prevails in looking at many ethical dilemmas in delivery of health care to individuals and society. It focuses on consequences of actions, on the greatest amount of happiness or the least amount of harm for the greatest number. This is a community-oriented theory in which each person counts equally, and consequences to future generations as well as other living individuals and groups are considered.

The utilitarian position is in conflict with the traditional medical ethic, which says that one should do all one can and mobilize all available resources for the individual patient.

Egoism. If one takes the egoistic position, one seeks the solution that is best for oneself. The nurse acting within an egoism framework would consider the solution that is most comfortable for him or her without regard to the benefits and harm to the patient, family, or any others. The solution may or may not be beneficial to the patient; however, the patient is not the primary consideration.

Formalism. In the formalist or deontological position, one would look neither at one's own personal position nor at the consequences of actions. Instead, one would consider the nature of the act itself and the principles or rules involved: never tell a lie; do unto others as you would have others do unto you; and so forth. Immanuel Kant is considered to be in the formalist tradition with his "categorical imperative" that one should act only on a maxim which one can apply in any similar situation(1). This is the principle of universalizability. One often hears a mother invoking this concept when she says to a misbehaving child, "What if everyone did what you'r doing?" Another version of the categorical imperative is that persons should always be treated as ends, never simply as means. In the recent past, people have been used as means in some research.

Fairness. Another position for consideration is presented by John Rawls, an important contemporary theorist on justice. Rawls talks about justice as fairness. According to his thinking, distribution of burdens and benefits should be considered from the point of view of the least advantaged in society; for example, children or the poor should share the benefits in society equally with all others. Benefit to the least advantaged becomes the norm for decision and policy making.

Rawls suggests that in considering the validity of moral principles one must look at the following:

- Universality. Principles must apply to everyone, and one must take into account the consequences if everyone complies.

- Generality. Principles must apply widely and not refer only to specific people or situations.

- Publicity. Principles must be publicly recognized by everyone involved.

- Finality. Moral principle is the final court of appeal and overrides the demands of law and custom on the basis of principle(2).

These criteria rule out all forms of the eogistic position from the moral point of view.

## Structure of a Dilemma

The process of structuring an ethical dilemma for purposes of clarification, decision, and, ultimately, action may take a variety of forms. One way that I have found useful in working with nursing groups is to break the dilemma into three elements--situational "facts," decision-making questions, and underlying ethical theories--and to view these elements within the context of time and value systems.

To clarify the elements, one must:

1. Elucidate the data base that one needs in order to do moral inquiry.
2. Consider the questions that come from decision theories.
3. Articulate the moral approaches, positions, or theories to be used in considering alternative action.

Value systems. The personal and professional value systems of the decision makers and of those affected by the decision will, of course, underlie the aboce three elements. For example, one person may consider that death is the worst that can happen to an individual, whereas another person involved in the same situation may feel that a severly handicapped life is a worse alternative when there is a choice to be made. Other values that may be involved in dilemmas for the nurse are those related to obedience and following physician orders, use of coercion to achieve certain ends, and the importance of patient self-determination.

Time. This is yet another dimension in clarifying dilemmas. Some dilemmas demand immediate action. Those in which time is less critical offer more opportunity for evaluating information as well as identifying and weighing options prior to action.

Data base. To examine an ethical dilemma, first of all one has to identify whether an ethical dilemma exists--especially when the dilemma is not as obvious as, for example, switching off a life support machine. Then, to gather the data base for ethical inquiry, the following questions should be answered as completely as possible:

1. Who are the actors involved? What are their histories and involvement in the situation?

2. What is the proposed action or actions?

3. What is the setting or context of the proposed action?

4. What is the intention or purpose of the proposed action?

5. What other alternatives or choices are available?

6. What are the probable implications or consequences of the proposed action?

This is different from the data base that nurses are accustomed to gathering, but it contains such familiar concepts as assessment, and it extends the reflective thinking process to an identified ethical dilemma. One may not have all the data available that one wishes to have in decision making. However, decisions often must be made without the ideal data base in the real world. Furthermore, even though the data base provides an essential component in consideration of an ethical dilemma, decisions do not simply spring from heaps of data.

Decision theory dimensions. The second element of the triad for structuring an ethical dilemma is to consider the following questions which come from decision-making theories:

1. Who should decide? The physician, nurse, patient, family, committee? Why?

2. For whom is the decision being made? Self, proxy, other?

3. What criteria should be used? Social, legal, physiological, economic, psychological, other? Why?

4. What degree of consent by the client or subject is needed? Freely given, coerced, none?

5. What, if any, moral principles are enhanced or negated by a proposed course of action? Self-determination, truthfulness, beneficence, justice as fairness?

In thinking about these questions, nurses and nursing students should also examine the concept of paternalism, or maternalism, as the case may be. When is the nurse interfering with a person's liberty and autonomy for the good of that individual in order to force what he or she, the health professional, considers to be a reasonable choice? When, if ever, do considerations for social good override the rights of the individual to make his own decisions about health care? These decisions may be easier in such situations as an epidemic of communicable disease where the community is clearly in danger. But they become particularly difficult and ambiguous when children, the mentally ill, or others determined to be incapable of decision making are involved: for example, in alleged child abuse situations or commitment of the mentally ill.

Ethical theory. The third part of the triad in structuring an ethical dilemma is to begin to articulate ethical theories or positions in looking at alternatives for action in a specific situation.

The decision maker who works from a strictly utilitarian position and the one who works from a deonotological position may come out of an ethical dilemma at two different places in terms of the most ethical decision. The strict utilitarian will resolve it by looking at consequences, calculating benefits, and acting for the greatest good of the greatest number. The strict deontologist will consider duties in relation to moral principles and "do what is right." Each position has limitations that need to be recognized by decision makers.

## Preventive Ethics

This structure can be used for consideration of ethical dilemmas in interdisciplinary and intradisciplinary learning settings. However, the dimension of available time is an important consideration in discussions of ethical dilemmas. Nurses and students need time in which to do reflective thinking of this kind.

It seems critical that nurses have planned opportunities, in an unharassed setting, to structure specific and recurrent ethical dilemmas so that they can go beyond the agonizing conflict of wondering what to do or hoping that particular events do not happen when they are "on."

The format of "ethical rounds" can be used to reflect on and clarify the elements of decision making and ethical issues and dilemmas in hypothetical or actual situations. They can also offer nurses an opportunity to discuss how ethical dilemmas and issues differ for the nurse, vis a vis other health professionals, and the patient in bureaucratic structures. Further, they can be used to bring medicine and nursing together to discuss and articulate the professional values and viewpoints each discipline brings to the situation.

One may take an additional step and ask, Are all ethical dilemmas that occur in nursing and health care inevitable? Is there such a thing as preventive ethics in nursing and health care? Such a concept could provide health workers with another way of considering ethical dilemmas.

For example, in nursing research involving human subjects, how many ethical dilemmas can be avoided through careful research design which would anticipate them? In practice, how many ethical dilemmas could be prevented through thoughtful assessment and careful listening to patients and families as they move through such difficult experiences as dying, living with a disability, or seeking painful information? Nurses are on this journey, too. To determine the anatomy of an ethical dilemma is to take the first step.

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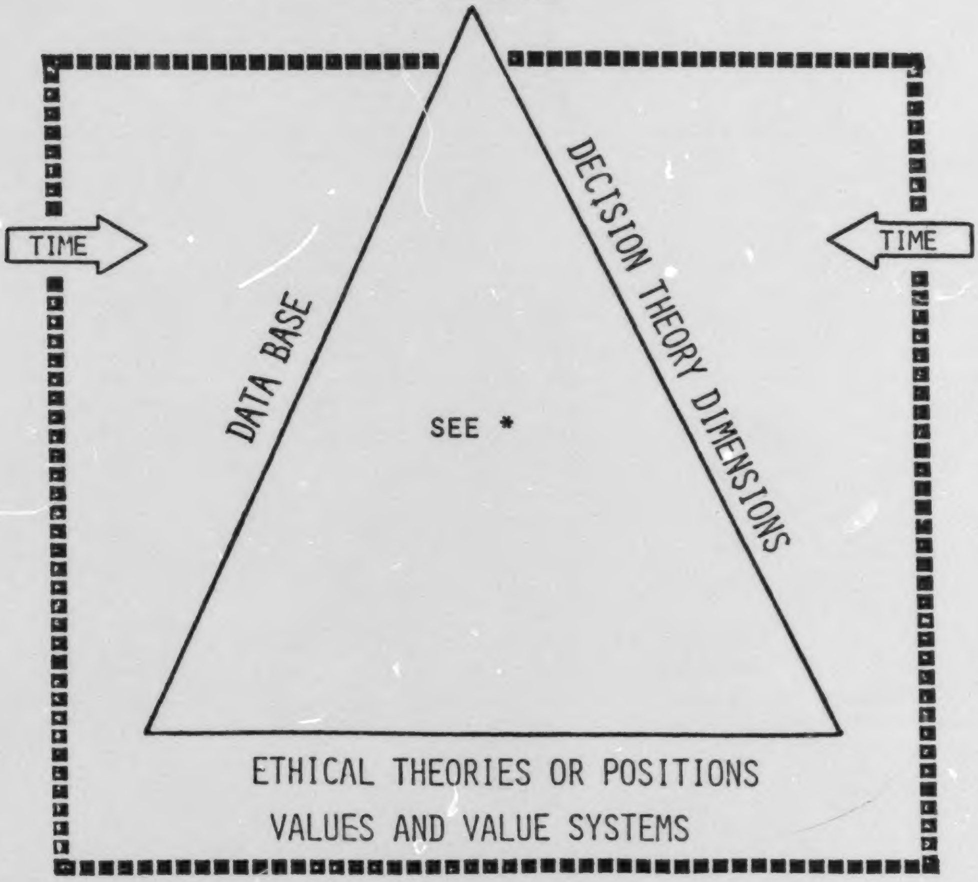
# ANATOMY OF AN ETHICAL DILEMMA: THE PRACTICE



*Ms. W, an 80-year-old widow, has been hospitalized with pneumonia. She has diabetes and progressive circulatory complications. She has been treating an ulcer on her left leg at home. She lives alone and has been very independent with minimal help from neighbors. While hospitalized for the pneumonia, she develops a diabetic gangrene of her left foot. Her physician has called a surgical consult. The surgeon decides that an above-the-knee amputation is necessary. Ms. W is adamantly against the amputation, saying that she wants to die "whole." A nurse overhears her conversation with the surgeon, and later Ms. W tells the nurse, "I'm not signing anything. I don't want my leg cut off." The surgeon says that he will have Ms. W's nephew sign for the amputation if Ms. W won't sign herself. He says that Ms. W is just "an obstinate old woman who doesn't know what's best for her." Ms. W's only other relative is a brother who has been in a state mental hospital for years. When the nurse expresses concern, the head nurse tells her that this is an issue between the patient and the surgeon and that she should not interfere.

The situation on the previous page presents an ethical dilemma for the nurse. She feels that she should do something as an advocate for the patient's right to self-determination, but the head nurse has made it clear that she should not interfere. As far as the staff nurse knows, the surgeon sees no alternative to the amputation, which he says is in the patient's best interest. The nurse is in conflict vis-a-vis the patient, the surgeon, and the head nurse.

Data base. To begin to dissect this dilemma, the nurse needs to gather as much data as she can about the situation, considering the questions in light of the people involved and the possible alternatives for action as well as their probable consequences. These do not exhaust all the possibilities, but the nurse should consider the following options: she can discuss the situation further with the patient, with the nephew, or with Ms. W's family physician, or she can take the head nurse's advice and do nothing. For each of these alternatives and combinations of alternatives, she must next consider the probable outcomes for all involved.

Decision theory dimensions. In addition to gathering the data, the nurse also needs to consider *who* should make the decision. Not everyone involved agrees that the patient should decide what happens to her own body. The patient claims that she should decide, while the physician claims that the decision is his, since he is doing what is in the patient's best interests, and he has the technical expertise.

A footnote, here, is that technical expertise cannot be generalized to the moral or ethical dimensions of a situation. In the hospital setting, the physician is in a position of power and authority; however, it cannot automatically be concluded that the physician or any other health professional is the best person to decide what is in the patient's best interest.

Even the courts have equivocated in situations involving the issue of rejecting treatment. A court might be asked to appoint a guardian *ad litem* for a decision about the proposed amputation *if* Ms. W had previously been declared "incompetent" by some stated criteria. But that is not the case here. Since Ms. W has not been declared incompetent by stated criteria, it is very difficult to morally or legally justify the nephew or the physician making this decision for her.

Next, the nurse needs to reflect on *what* criteria should be used in choosing an alternative for action. For example, she might consider only Ms. W's physiological or medical status and choose to do nothing because she is convinced that only the physician can assess the medical indication for the amputation.

In terms of nursing's emphasis on the whole patient and the proclaimed role of the nurse as patient advocate, the nurse should also take into account the psychological, social, and spiritual dimensions of what the amputation means to Ms. W on a short- and long-term basis. In addition, she might take into consideration the economics of the situation and project the possible financial implications if Ms. W does or does not have the amputation. For example, what kinds of support systems might Ms. W need if she has the amputation and how will they be financed? The nurse might also think about the ordinary- versus extraordinary-means distinction. Although this may appear to be important, it is often not very helpful in actually making decisions. What is ordinary in a large teaching hospital may be extraordinary in a small hospital. Identical treatment, such as giving antibiotics, may be ordinary in one situation and extraordinary in another.

If Ms. W did sign the consent form, the nurse might be concerned as to whether the decision was coerced by the nephew or the physician or freely made by the patient. This is not always an easy determination, but if the patient expresses doubts after signing the consent, the possibility of coercion and its implications need to be considered.

Additionally, the nurse would consider whether the possible alternatives enhanced or negated such principles as the patient's right to self-determination and the principle of beneficence or nonmaleficence. The latter principle says that one should not inflict harm or evil and that one ought to prevent harm, particularly intentional harm, or the risk of harm. This principle applies to patients and also requires that such agents as the physician and nurse are thoughtful about their actions and consider them in the light of professional standards. The nurse would judge which alternative best serves Ms. W, taking into consideration the standards of nursing practice.

Ethical Position. In considering various approaches, the nurse can look at the alternatives from different ethical theories or positions.

From a strictly utilitarian point of view, one would consider the possible consequences of each alternative and decide which alternative would provide the greatest amount of happiness or the least amount of unhappiness for all concerned. For example, if she decides to do nothing, the physician, the nephew, and the head nurse presumably will be "happy" because the best interests of the patient, according to their assessment, have been served. Indeed, in some situations in which the physician has overruled the patient, the patient has been grateful later. One may not find this approach acceptable for a variety of reasons, including the lack of respect for the individual's autonomy. However, a strictly utilitarian approach might justify an alternative not justifiable under another ethical approach.

The strict deonotologist would say that there are moral principles that apply, regardless of the consequences. In Ms. W's situation, if the nurse firmly believes in a principle of respect for the individual's right to autonomously make decisions about his own life and body, the option of doing nothing to prevent others from forcing a decision on Ms. W would not be justified. Also, in this context, doing nothing negates the principle of nonmaleficence by "allowing" an action that is harmful to the patient in the sense that her dignity as an individual will be violated and her body invaded without her express consent. For this nurse, a decision to do nothing would conflict with her moral principles. If, on the other hand, this nurse accepts the physician's opinion that the patient will die without the amputation and she believes in the value of maintaining life over individual autonomy, she may decide to participate in forcing Ms. W to have the leg

| | **Data Base** |
|---|---|
| Who are the actors involved? What are their histories and involvement in the situation? | Patient--advised by the surgeon that she must have an amputation to treat diabetic gangrene, has refused and stated she wants to die "whole"; Hospital staff and consulting surgeon--interested in providing care to prolong the patient's life, little or no involvement with patient as a person, unlikely to have any future involvement with patient as a person; Head nurse--interested in running a smooth functioning unit; Primary nurse--no prior involvement with patient; Nephew--not emotionally close to patient prior to her hospitalization; Family physician--has cared for the patient for almost 10 years |
| What is the proposed action? | To amputate Ms. W's leg--with or without her consent. |
| What is the setting or context of the proposed action? | The patient has gone from relative independence at home to dependence in the hospital. Amputation of her leg may impede her ability to continue her prehospital independence. The patient is in an acute care setting so the staff's involvement with her and her family will probably be short-term and whatever happens is not likely to have long-term effects on them. |
| What is the intention or purpose of the proposed action? | To prolong Ms. W's life. |
| What other alternatives or choices are available? What are the probable outcomes of each alternative and combinations? | • Discuss the situation further with the patient and try to persuade her to sign the consent for amputation. *Outcome?* Patient might consent if she can explore options without pressure or she might see the nurse's action as more pressure and become more adamant in her refusal.<br>• Discuss the situation further with the surgeon and bring up the Patient's Bill of Rights posted in the hospital admissions office. *Outcome?* Surgeon might recognize the patient's right to make the decision and discuss it further with the patient or he might announce he doesn't believe in the bill of rights and inform the nurse it has no legal weight anyway.<br>• Try to get in touch with the nephew before the surgeon contacts him. *Outcome?* Nephew might tell the surgeon and the surgeon might accuse the nurse of trying to subvert the physician-patient relationship.<br>• Inform Ms. W's family physician of Ms. W's feelings about the proposed amputation. *Outcome?* Physician might say there isn't anything he can do since the amputation is absolutely essential.<br>• Take the head nurse's advice and do nothing. *Outcome?* Nurse might avoid the risks of taking action and get along better with everyone or she might be seen as nonassertive. |
| What are the probable implications or consequences of the proposed action? | If the surgery is done without Ms. W's consent, she may retaliate aggressively by obtaining legal representation or passively by refusing to participate in the postoperative rehabilitation. |

## DECISION THEORY DIMENSIONS

| | |
|---|---|
| Who should decide? Physician, nurse, patient, family, committee? Why? For whom is the decision made? Self or other? | • The patient should decide what happens to her own body.<br>• The physician should decide for the patient, since he is doing what is in her best interests, and he has the technical expertise.<br>• If the patient has been declared incompetent by some stated criterion, a guardian *ad litem* appointed by the court should decide for the patient, since the patient is unable to decide for herself. |
| What criteria should be used in deciding who makes the decision? Social, legal, psychological, physiological, economic? | The nurse might:<br>• Consider only Ms. W's physiological or medical status and choose to do nothing because she is convinced that only the physician can assess the medical indication for the amputation.<br>• Consider Ms. W's legal right, in the absence of an emergency or declaration of incompetency, to consent and help her get a lawyer.<br>• Assess Ms. W's psychological reaction to amputation without her consent and try to delay the surgery until the patient agrees. |
| To what degree must client *freely* consent? | What is the impact of consent obtained through coercion by the nephew or physician versus consent without coercion? |
| What, if any, moral principles are enhanced or negated by a proposed action? | • Abiding by the patient's refusal enhances the patient's right to self-determination; overriding it negates the right.<br>• Obtaining the patient's consent enhances the principle of beneficence or nonmaleficence, as well as truthfulness. |

## ETHICAL THEORIES AND POSITIONS

| Theory | Consideration | Decision-Making Logic |
|---|---|---|
| Deontological Ethics/Formalist Ethics | The principles involved in the action: objective is to act "correctly" according to a moral principle regardless of the consequences | There are moral principles that apply regardless of the consequences. If the nurse does nothing, she "allows" an action which is harmful to Ms. W in that her dignity as an individual will be violated and her body invaded without her consent. To do nothing conflicts with a principle of respect for the individual and her autonomy to make decisions about her own life and body. The nurse, coming from this ethical position, *must do something*. |
| Utilitariansim | The consequences of action on all involved now and in future: an action per se is neither right nor wrong, it becomes right when it produces the greatest happiness or the least harm for the greatest number. | To decide on an action, the consequences of each alternative must be considered and the one that provides the greatest happiness or the least harm for the greatest number selected. If the nurse does nothing, the physician, nephew, and head nurse will be "happy" because the patient's best interests, in their view, will have been served. |
| Egoism | Consequences of action on decision maker: objective is to act so as to achieve the greatest happiness or least harm for self. | To decide on an action, the consequences of each alternative must be weighed in terms of the greatest good or least harm to the decision maker. If the nurse views herself as a patient advocate and does nothing, she risks psychological harm. If nursing is a job, she will take the head nurse's advice and do nothing. |

amputated.

Further, one can look at each alternative in light of whether or not it meets the tests of universality, generality, and publicity. Is the patient being treated as an end as well as a means? or is the patient being used to satisfy a health professional's ego needs? Is the nurse willing to let all involved know what she is doing? Is she willing to universalize this choice to others in similar circumstances?

Using a rights approach, the nurse might claim that she has the right and responsibility to be an advocate for the patient's point of view. She would choose an alternative that creates a situation in which the patient's feelings are made known and respected by all. The patient's right to reject treatment would be respected with the caveat that her decision was made after careful deliberation.

## Dimensions of Time and Values

Identifying the values of all involved in the situation is another dimension of clarifying a dilemma. If this nurse values obedience to those above her in the bureaucracy, she will follow the advice of her superior in the nursing hierarchy, the head nurse, and do nothing. If the nurse values self-determination for herself as a professional person and for clients as an overriding value, she will be unable to justify doing nothing; she will choose an alternative expressive of this value. The nurse, the patient, and other health workers may hold different values about the nurse's role, about living with a mutilated body, or about any other factors involved.

The time element in Ms. W's situation is not as critical as in such situations as a cardiac arrest, in which the decision to resusicate or not to resuscitate must be made in a very limited period of time. The nurse could use this framework for analyzing a dilemma either alone or with a colleague to reflect on Ms. W's situation and available options. She might even use it for a discussion with Ms. W's physician.

How and when a nurse looks at the anatomy of an ethical dilemma is related to time and values. Because of time, dilemmas must sometimes be resolved now and dissected later. But whether the nurse in Ms. W's situation analyzes the dilemma before or after acting may be more closely related to her values. Nurses hold different values in relation to using a deliberative and reflective thinking process *prior* to making decisions versus justifying decisions and actions *after* the fact. Thoughtful and careful reflection *before* taking action could fulfill one aspect of the principle of nonmaleficence, that is, preventing intentional harm.

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# ETHICAL ANALYSIS OF A NURSING PROBLEM: THE SCOPE OF NURSING PRACTICE IN DISCLOSING THE TRUTH TO TERMINAL PATIENTS

An Inquiry directed to the National Joint Practice Commission
of the AMA and the ANA

Part I

Rod R. Yarling

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# ETHICAL ANALYSIS OF A NURSING PROBLEM: THE SCOPE OF NURSING/PRACTICE IN DISCLOSING THE TRUTH TO TERMINAL PATIENTS

An Inquiry directed to the National Joint Commission
of the AMA and the ANA

## PART I

Roland R. Yarling

## CASE PRESENTATION*

Mrs. X, a recent divorcee in her mid-forties, was a female Caucasian patient with a diagnosis of cancer of the colon with metastasis involving the lymph nodes. Upon her admission to the hospital she was assigned to a surgical oncology unit where primary nursing care is practiced. A young staff nurse with considerable oncology experience (three years in another hospital and two months in this unit) was assigned to her as her primary nurse. She cared for the patient for three days preoperatively and established good rapport with her. The day of surgery, she cared for her post-operatively, but there was very little communication due to the patient's heavily sedated condition.

The day after surgery the nurse was off duty. The second post-operative day she returned, but could not determine what the patient had been told about her condition. A check with her associate nurse revealed that the patient had requested no information about her condition from her, and that she had volunteered none. The chart contained no record of what, if anything, the patient had been told by the physician. Moreover, the physician was not immediately available for clarification of the matter.

Consequently, she began the patient's care with the question unresolved. However, it soon became apparent that the patient had not been informed that the tumor was cancerous and that it had mestastasized. She did not know the seriousness of her condition. It was also apparent that she was concerned. She complained of sharp pain in the abdomen, asked for information about the results of certain tests that had been done, and wanted to know how soon she would be able to return to work. When the nurse judiciously avoided a direct answer to these questions, she asked directly, "Is everything all right?"

At that moment two daughters, who were present when the patient was asking these questions, broke into the conversation with diversionary remarks. A few seconds later, when the nurse left the room, one of the daughters followed her out to ask her to assure the patient that there was nothing to be concerned about. She said that their mother had just gone through long and difficult divorce proceedings and that they did not want her to be further burdened with the knowledge of her condition.

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*The above situation was related to me by a nursing services supervisor in a university hospital in the Chicago area. I am indebted to her for reconstructing the course of events in the situation described.

The nurse listened, but offered no assurances in that regard. Clearly, the physician had talked with the family about the situation, but not with the patient. She discussed the situation with her head nurse, who suggested that she consult with the attending physician about the matter as soon as possible.

She resumed the patient's A.M. care, attempting to keep the conversation on the light side until she had an opportunity to consult the physician. Shortly, a group of surgical residents entered the room and asked the patient how she felt. She told them, "Fine." They examined her without further comment, except among themselves, and left with the parting remark that she was "looking good." The nurse left the room with the residents and asked them if they knew what the patient had been told about her condition. She was informed that she would have to ask the attending physician about that.

In a few minutes, the attending physician appeared, greeted the patient, and asked her how she felt. She indicated that she felt "pretty good" and asked no questions. He examined her briefly and left. (The attending physician was not a long standing personal physician of this patient, and therefore, had no pre-established rapport with her.) Soon thereafter, the nurse found the attending physician at the nurses' station. She told him that she was caring for the patient and that she would like to know what the patient has been told about her condition, so that she might be more open and supportive with her. She also mentioned the requests which the patient had made to her for information about her condition.

The physician's response was twofold. First, he said that the patient had not been told that she had cancer and that she was not to be told because this would only cause her unnecessary anxiety. Second, he informed the nurse that he would consider any act of disclosure on her part to be inappropriate to her role as a nurse and inconsistent with the well-being of the patient. The general tone of the physician's response was disapproving.

At that point, the young nurse retreated to the head nurse who assured her that she had not acted inappropriately and that she should not take the rebuff personally. The head nurse acknowledged, however, that the physician's actions created a serious dilemma. She said that she had been confronted with this same situation with this physician before and that she was never quite sure how to handle it. After a moment of apparent indecision, she advised that it was probably best to follow his rules and deal with the patient's questions accordingly. After the nurse had time to think the situation through and get all the relevant considerations in view, she came to the conclusion that the patient had a right to have her questions answered and that she should answer them directly and honestly. She thought this would serve the best interest of the patient, and she was very uncomfortable lying to a patient who had come to trust her. However, because she did not have great confidence in her convictions, she was hesitant to act contrary to the wishes of the family, the physician, and the head nurse; and, she was not sure what her legal rights were in the situation. So, she acquiesced uneasily.

## CENTRAL ISSUES RAISED BY THE INCIDENT

### INTRODUCTION

The ethical issues present in this simple incident are paradigmatic of ethical issues in nursing. The incident raises questions about important issues which arise daily among nurses and physicians, but which are rarely addressed in a direct manner conducive to constructive and satisfactory resolutions. The following presentation attempts to address the issues in that manner.

On the basis of this incident a question is posed herein for the consideration of the National Joint Practice Commission, but the analysis which follows the question is not neutral. A position is argued with respect to that question. However, there is no intention to pre-empt the Commission's function of assessing and judging the question which is posed. The assumption is that the Commission can respond more directly to a clearly stated position than to a simple question. Therefore, an effort is made to argue a certain position as clearly and cogently as possible in the hope that this will assist the Commission in its deliberation on the question.

The problem under discussion is a frequently recurring problem of great significance, profoundly affecting the lives of countless patients and their families, as well as nurses and physicians. An analysis and discussion of the problem and some movement toward resolution is long overdue. It is hoped that this paper and the response of the Commission will contribute to a resolution of the question posed herein.

### A Formulation of the Issues

The incident described generates many issues, but the intention here is to identify and clarify the central ones with which we are concerned, and as far as possible, discern the shape of the answers. The central issues which emerged in the course of conversations with several colleagues[1] are:

What are the rights of the patient to information about his own condition in a case of terminal illness?

Is the disclosure of diagnostic and prognostic information to terminal patients an act proper exclusively to the practice of medicine, or is it an act proper also to the practice of nursing?

## PATIENTS' RIGHTS

### Patients' Legal Right to Information

There are two kinds of rights: moral and legal. With regard to the question of the patient's legal right to information about his diagnosis and prognosis, let us begin with the situation in Illinois where the law is relatively liberal on this point, and then look at the more general picture in other states. In Illinois the law is quite clear. Under a recently revised statute (1976), the hospital patient has no legal right to routine access to information in his medical record until after his discharge.[2] Even though the patient has no legal right to routine access, the health care practitioner does have a legal obligation to provide whatever information is required for informed consent to any procedure which may be proposed for diagnosis or treatment. If some chemical or radiological treatment had been proposed for the patient in this case, then she would have had a legal right, under the principle of informed consent, to information regarding the reason for the treatment, the expected effect of the treatment or prognosis, the nature and possible consequences of the treatment itself, and possible alternative treatments.[3] However, the patient in the incident had no legal right, according to the Illinois statute, to the information which she was requesting as long as she was a patient in the hospital, and as long as no treatment was being undertaken.

Under this statute, however, a patient's right of access to information changes after he is discharged from the hospital. He then has a legal right to a copy of all hospital records pertaining to his care. The only stipulation, under the statute, for obtaining a copy of these records is that a written request for them must be submitted to the hospital administrator. The services of an attorney are no longer required for this transaction, as was previously the case.[4]

As restricted as the legal position of the patient in this situation is in the state of Illinois, it is similarly or more restricted in most other states. An excellent summary of the patient's rights in this regard in various states is provided by George J. Annas:

> In 41 states the only legal right you have to see your medical records is by instituting a lawsuit against the hospital or doctor involved in your care and having the records subpoenaed for evidence. This procedure has been severely criticized by the Report of the Secretary's Commission on Medical Malpractice as needlessly increasing the number of malpractice claims filed.

Only nine states have laws that give the patient or his attorney the right to inspect hospital records. Of these, California, Illinois and Utah limit access to the patient's attorney.[5] In the other six states, Massachusetts, Wisconsin, New Jersey, Louisiana, Mississippi and Connecticut, patients may have direct access to their records under various circumstances. Perhaps the most liberal statute, that of Massachusetts, provides that the patient's medical records "may be inspected by the patient to whom they relate....and a copy shall be furnished upon his request and a payment of a reasonable fee."[6] Occasionally, one will hear of a hospital here or there experimenting with a policy of giving patients free, open, and routine access to their records, but in general, it remains true that patients do not have a legal right to routine access to their records or to any other mode of information regarding their diagnosis and prognosis.

### Patients' Moral Right to Information

With all due regard for the law, it is imperative to recognize that legal rights are one thing, and *moral* rights are quite another. Consequently, a clarification of the legal situation does not necessarily resolve the moral question. A moral right may exist where there is no legal right, and vice versa. The situation under discussion is a clear instance of this dichotomy. Patients do have a moral right to all such information, and if they exercise that right, i.e., request the information, it should be provided to them. Arguments in justification of this moral right are presented later, but there is one point which requires clarification here. There is an important distinction between rights and obligations. In discussions of patients' moral right to information about their condition, there is sometimes a tendency to collapse this distinction. This happens when one assumes that having the right (or freedom) to know something is equivalent to being obligated (or required) to know it. That assumption is incorrect. A patient has *no obligation* to know about his diagnosis and prognosis if he does not want to know and expresses no desire to know. He does have a moral right to such information, and when he asks for it, it should be provided. There are, of course, other equally important psychological questions about when and how such information should be disclosed, but these questions are not central to the present line of inquiry.

## THE SCOPE OF NURSING PRACTICE

### The Significance of the Question of Scope in Relation to the Disclosure of Information

Given the foregoing legal and moral considerations pertaining to patient rights, the situation described in the case presentation raises the second of the two issues posed in section two. It is the question of the scope of nursing practice as it relates to the disclosure of diagnostic and prognostic information to terminal patients. This question is a source of intense and ongoing concern to a wide range of both physicians and nurses, but it remains unsettled in most quarters, constituting a barrier to good patient care.

The issue is a most significant one. It is a key piece of a large and complicated puzzle. If we outline the larger picture, the significance of this particular issue will be revealed. The theme of the larger picture is professional dominance. The keystone of professional dominance is the professional control of information. Absolutely essential to the professional control of information is the full and faithful cooperation of the nurse. If the nurse cannot be bound morally, legally and professionally to the strict observance of the protocol through which the professional control of information is maintained, the entire foundation of professional dominance crumbles away.

If, therefore, the patient has a right to know his diagnosis and prognosis, and all other information relevant to his treatment and care, and if the nurse happens to be sensitive to this right, then a serious conflict exists between the nurse and the professional system. The covert issues of patient rights and professional dominance notwithstanding, the issue will invariably get defined as an honest difference of opinion about what is in the best interest of the patient. Given the fact that this issue cannot be settled by an appeal to clinical evidence, and given the further fact of existing power relations between nurses and physicians, the patient will not be told, the professional control of information will be maintained, and professional dominance will prevail.

The intent of this analysis is to redefine the underlying issue. The basic issue is not a paternalistic debate among professionals about what is in the best interest of the patient. It is rather the question of whether the patient does indeed have a right to such information. If this is understood to be the basic issue, then the question of the nurse's role in the disclosure of information is not just an inter-professional squabble, but an issue fundamental to the quality of patient care. Further, the question of the nurse's role in situations like the one described cannot be satisfactorily resolved without making a commitment on the underlying moral issue of the patient's right to know.

The moral problem of the patient's right to know takes the following form. When all attempts by a nurse and a doctor, and their respective colleagues, to reach agreement on a patient care decision have failed, how is the matter to be resolved? In most cases, the final decision ought to be made by the patient. However, in this case, the patient's position was already known. She wanted to know. Therefore, the moral issue is confronted: assuming that the patient has a right to know,[7] at what point should professional collegiality and solidarity between nurse and doctor become secondary to concern for the self-determination of the patient when these two principles come into irresolvable conflict? At what point should the nurse's commitment to the patient's right to know take precedence over the customary practice of nonintervention in the patient-physician relationship? Appeal to the ambiguous principle of doing what is best for the patient solves nothing. It is out of that ambiguity that the question arises. What is required is a decision on the basic issue of the patient's right. Does the inquiring patient have a moral right to have his questions answered, and if so what is the legitimate role of the nurse in honoring that right?

Despite the significance and universality of this question, and its underlying issues, very few practitioners have any clear idea of what the legal, moral and professional status of the nurse is in a situation such as the one presented. This is due largely to the fact that no one has heretofore persistently pressed this specific question toward a resolution in its legal, moral, and professional dimensions.[8] There is a body of literature which discusses patient's rights to information regarding their condition and care, but there is no systematic discussion of what the role of the nurse should be in disclosing that information.[9] Furthermore, the policies of different health care institutions differ widely and impinge with great force upon particular situations. This institutional variability, combined with the uncertainty of individual nurses, effectively undermines the autonomous functioning of most nurses with regard to protecting patient rights and precludes a collegial relation with physicians. Collegiality necessarily presupposes collaborative autonomy.

The main point to be drawn from the foregoing is that the question being posed for the Commission regarding the scope of nursing in disclosing of information to patients is not just a simple question of professional boundaries subject to resolution in procedural terms, but involves a fundamental moral problem in patient care. The nature and significance of the question makes it highly appropriate for consideration by the National Joint Practice Commission. The underlying issues, identified above, make it a politically sensitive question, but it must be addressed in the interest of good patient care. A clear, substantive response from the Commission on this question should be of considerable value in defining the situation and influencing institutional policy. It is, of course, not possible for the Commission or anyone else to generalize about such matters in a way that eliminates the necessity for informed and balanced judgments in particular cases. However, this question involves issues of such fundamental importance to good patient care that it is imperative for the nursing and medical professions to agree upon some principles, e.g. the patients' right to information, to which practitioners may look when making judgments in particular cases. The National Joint Practice Commission is an appropriate body to undertake this admittedly difficult task.

## Conditions and Considerations Giving Rise to the Question

The best way to indicate the import of this question is to set forth, in a series of statements, that combination of conditions and considerations out of which it arose. They are as follows:

a. If a patient does not have a *legal* right to the information which he is requesting, and in this case, the patient did not; and,

b. If a patient does have a *moral* right to this same information, and patients do have a moral right to all available information regarding their condition; and,

c. If a patient exercises that moral right by requesting the information, and in this case the patient clearly and repeatedly did ask about her condition;[9] and,

d. If the physician repeatedly and emphatically refuses to provide the information, or to allow it to be provided, and in this case he did;[10] and,

e. If the family wishes to have the information withheld, and in this case they clearly did;

f. Then, what are the rights and obligations of the nurse who is caught in the middle of these conflicting interests? To whom is she responsible? What actions are required, permitted, or prohibited, and on what grounds? What is the appropriate relation among her legal, moral, and professional responsibilities?

## Legal Situation of the Nurse

Given the situation described, and the questions inherent in it, the resulting predicament of the nurse in that situation can be further specified.

Because the patient had no legal right to the information which she was requesting, no one had a legal obligation to provide it. However, the absence of an obligation is not equivalent to the presence of a prohibition. There was no legal prohibition against providing the information, at least not for the physician. Moreover, all other considerations aside, it would probably have been legally prudent for the physician to provide the information. No court has ever held a physician liable for providing a patient with too much accurate information, regardless of the consequences.[11]

The legal status of the nurse in this situation is more ambiguous. She was under orders from the physician not to disclose information to the patient about her condition, but her professional judgement was that the patient's questions should be answered. The question is then: What are the legal rights and obligations of a nurse in such a situation?

## Moral Situation of the Nurse

The determination of professional responsibilities should rest upon moral as well as legal considerations. When the case under consideration is viewed from a moral, rather than a legal, perspective, a different set of issues comes into view. Patients in situations such as this, as already noted, generally have no legal right to information about their condition, but they do have a moral right to that information. Because they do have that moral right someone has a corresponding moral obligation to provide it to them. Who has that moral obligation?

Moral obligation (or responsibility) is self-distributing, non-transferrable and transcendent to lines of institutional responsibility. The imperative for moral action rests inescapably upon all who are aware of the conditions which mandate the action. A person cannot absolve himself from the responsibility to act morally by transferring it to another person within the authority structure of an institution. This is true whether that institution be military, governmental, economic, or a service institution such as a hospital. Therefore, in this case the moral obligation to provide the information rested equally and inescapably upon anyone who possessed the information, had the competence to disclose it, and was requested by the patient to disclose it.

However, there were certain hindrances to the act of disclosure which restrained all the various actors in this situation. The family withheld the truth in the well-intentioned (if not well-considered) decision to protect the patient from further hurt. Presumably, the physician was acting from similar motives. It is also possible that both the family and the physician were motivated to some degree by the desire not to confront the situation themselves, or at least not to face it with the patient. On the other hand, the nurse, while also being concerned with the welfare of the patient, believed that a consideration of the patient's rights, as well as of her welfare, indicated that she should have the information she requested. Furthermore, she was uncomfortable with the practice of not being candid with patients. Her feelings have a sound basis in the view that trust is an essential ingredient to a therapeutic relationship between a patient and a professional. Unfortunately, the frequent practice of attempting to deceive terminal patients has already contributed much to the distrust of both the medical and the nursing professions. (This point will be developed later.) However, her own view on the matter notwithstanding, the nurse was under orders from the physician not to tell the patient about her condition. Consequently, she was constrained by an uncertainty about her professional responsibility. She found herself in a dilemma in which her moral responsibility to the patient, as she understood it, required her to do one thing; her traditionally defined responsibility to the physician required precisely the opposite; and her legal status in the situation was clearly unclear. In a situation such as this, where does the nurse's highest professional responsibility lie?

## MORAL ISSUES VERSUS MEDICAL ISSUES

### Scope of Practice Apart from and Contrary to Physicians' Orders

The acute predicament of a conscientious nurse in a situation like the one described above gives rise to the following analysis. In order to facilitate the analysis, let us refine the question about the scope of the nursing practice by breaking it down into two questions. First, there is the question of whether the disclosure of sensitive information to a patient, in a case such as this, is proper to the practice of nursing in the sense that it may be done routinely on the basis of a competent and independent nursing judgment apart from the physician's orders. This should not be taken as a question about the necessity for communication and consultation among members of the health care team. The necessity for that is assumed. The question is about what is permitted on the basis of a competent and independent nursing judgment, given a context of communication and collaboration among all persons involved in the care of a patient. Before responding to this, let us pose a second question, which is a significant variation on the first. The response which is developed applies equally to both.

The second question which the situation raises is that of whether the disclosure of such information to a patient is proper to nursing practice in the sense that it may be done on the basis of a competent and independent nursing judgment contrary to the orders of the physician. This assumes that the physician has resisted persuasion, by all parties, to share the information with the patient. It may appear to some that the rather obvious answer to this question is that the nurse ought to comply with the physician's orders. However, there are some serious issues involved here that cannot be dismissed so readily. These issues are related to the distinctive nature of the problem in the question which we have posed regarding the role of the nurse in the disclosure of diagnostic and prognostic information.

A clarification of how this problem is different from other seemingly similar problems will illuminate the crucial issues. There is nothing new or different in the ongoing inquiry into what is proper to the practice of nursing and what is not. That is a standard topic related to the increasingly technical character of patient care as it has evolved in both the nursing and the medical professions. It arises in relation to a broad range of specific actions which sometimes are, and sometimes are not, considered proper to nursing in various institutions and localities, such as the administration of intravenous therapy, defibrilation, intubation, etc. However, in a situation where the problem is that of the disclosure of diagnostic and prognostic information to a terminal patient, there are significant issues which are not present in a situation where the problem is, for instance, that of intubating a patient.

## The Situation with Respect to Intubation: the Question of "Who"

Consider a situation in which the problem is that of intubation. With respect to such a procedure, the question is usually not one of whether it should be done, but rather of who should do it. If the prevailing practice is that nurses do intubate patients, then when a patient developes symptoms of respiratory failure, the nurse in charge routinely makes the decision to intubate, preferably in consultation with the physician if he is available, and performs the procedure. There is no problem so long as the nurse and the physician are in agreement on the need for the procedure.

When the prevailing practice is that nurses do not intubate patients, the scenario changes slightly. If a patient requires intubation (and frequently the crucial decision that the procedure is necessary depends in the first place upon nursing observation and judgment), the physician is called, the nursing judgment is confirmed, and the patient is intubated by the physician. The nurse who is capable of, and perhaps experienced in, performing the procedure may regard the calling of a physician as an unnecessary complication, but it does not, at least under ordinary circumstances, constitute a detriment to the quality of patient care, and it does not compromise her commitment to the patient. The necessary procedure is performed. Again, there is no problem as long as the nurse and the physician agree on the need for the procedure.

Regardless of what the prevailing practice is concerning who may perform intubations, if there should be a disagreement between a physician and a nurse about whether an intubation is necessary, then the opinion of the physician clearly ought, in ordinary circumstances, to be the determining factor. A decision that a patient should be intubated is based upon an assessment of the patient's medical condition and the physician's judgment in this area is generally considered to be superior to that of the nurse. This is not to say that nurses should obey physicians' orders uncritically. If the physician orders something done or proposes to do something potentially harmful to the patient, it is the moral and legal responsibility of the nurse to exercise her independent, professional judgment in the matter and take whatever action is necessary or possible for the protection of the patient. However, the general point stands that, with respect to decisions based upon medical knowledge, the judgment of the physician ought ordinarily to be preferred by reason of his medical expertise.

## The Situation with Respect to Information: the Question of "Whether"

There are decisive differences in a situation where the issue is that of the disclosure of diagnostic and prognostic information to a terminal patient. Here the central question ordinarily is not who should inform the patient, but whether or not the patient should be informed. It is assumed by many that only the physician ought to make the disclosure if it is to be made. That is the assumption under question here. The problem of "who" becomes a presssing question chiefly because of disagreement about the prior question of "whether." These two questions are so inextricably related here that it is impossible to deal adequately with one, without giving serious attention to the other. First, let us consider the more fundamental question of "whether."

The Nature of the Question: The first issue to be settled in discussing the question of whether or not a terminal patient should be told of his condition, is the very nature of the question itself. This question and the question of whether a patient should be intubated are questions of entirely different orders, and the considerations which determine their proper resolution are likewise of different orders. Assuming the consent of the patient, the question of intubation is a medical question which should be resolved on the basis of medical considerations. The question of disclosure, on the other hand, is a moral question which should be resolved on the basis of moral considerations. Certainly, the action of informing a patient about his condition requires medical knowledge, that is knowledge of the disease, its consequences, and possible therapeutic or palliative measures, as well as appropriate psychosocial skills. Nevertheless, the decision to inform remains a moral decision rooted in the recognition of the patient's moral right to such information. Moral decisions should not be made on medical grounds, nor medical decisions on moral grounds.

It is argued by some that providing terminal patients with information about their condition has deleterious consequences for them, at least psychological, and perhaps medical, in nature; and that it is, therefore, a medical decision. That position is difficult to sustain for various reasons. The premise that such information has deleterious psychological and medical consequences in a significant number of cases is not impressive, especially in the case of terminal patients who are specifically requesting information about their condition. This is not to suggest that the news that one is terminally ill is not devastating news to many, if not most, people. However, if they are specifically and directly requesting such information, there is a strong paternalism involved in taking the position that they probably are not capable of dealing with the information which they seek. Consequently, the practice of not disclosing and discussing the situation directly with the patient usually succeeds only in isolating the patient and undermining the integrity of even his most intimate and significant relationships with family and close friends. Participation in this destructive process is not consistent with a professional commitment to the well-being of the patient.

More to the point, however, than the question of whether such decisions have deleterious consequences, is the fact that the nature of a decision is not defined by its consequences. For instance, the decision about the distribution of scarce medical resources, e.g., dialysis machines, clearly had life-and-death medical consequences for many persons, but it is not a medical decision based on medical considerations, at least not in those cases where the candidates for treatment are relatively equal with respect to their medical condition and their chances for survival. Another case in point is a governmental decision about allocation of funds for such things as medical research and equipment. These decisions have medical consequences, but they are moral-political, not medical, decisions. So it is with the decision about whether or not to disclose information to a terminal patient. The act of informing may require a degree of medical knowledge, and it may possibly have medical consequences, but it should not be based on medical criteria. It is, rather, a moral decision based on the recognition of prevailing rights and obligations.

Non-medical Questions and Medical Expertise: The significance of the point about the nature of the decision is that it has direct implications for the qualifications of the decision-maker. Because the question is non-medical in nature, if there is a disagreement between a nurse and a physician about whether a terminal patient who requests the information should be told of his diagnosis and prognosis, the matter of whose opinion should prevail is not as clear as it is in the situation where intubation is the question. There, because the judgment is medical in nature, the expertise of the physician is preponderant. Here, however, because the judgment is non-medical, the medical expertise of the physician does not give his opinion any extraordinary value. The question of whether to inform the terminal patient of his condition is essentially a moral one, and decision on that question is a moral, rather than a medical, decision. This being so, neither the physician, as physician, nor the nurse, as nurse, may claim a privileged position with respect to making that judgment. To assume that they may is to commit the fallacy of the generalization of expertise. Expertise in one area does not necessarily translate into expertise in another area, nor into wisdom with respect to the larger questions of life. Therefore, in relation to questions such as this, the nurse and the physician stand, other things being equal, as morally equal and responsible members of a highly specialized scientific community committed to the care of patients. In the process of caring for patients they are almost routinely confronted with the most profound of moral questions. It is to the great peril of everyone involved that we fail to recognize that these moral questions are not within the special province of the scientific expertise of the highly specialized patient-care community.

The Relevant Decision-making Community: The question of whether to inform a terminal patient of his condition is typical of a broad range of moral questions which have arisen from modern, scientific medicine, but which are not soluble in scientific or medical terms. The medical, nursing, and allied helping professions are confronted daily with these issues whose resolutions are not, by their very nature, the responsibility of just the patient-care community, but also of the larger, public community. Though decisions on individual situations must, for the most part, continue to be made by those on the front lines of patient care, they ought to be informed by and reflective of the concern and debate of a broad, deliberative, public forum where the ramifications of such issues can be thoroughly explored from a variety of perspective. Those making these decisions must understand the nature of the questions before them, observe the limits of their professional perogatives with respect to these questions, and allow their decision-making to be informed by a community of moral discourse which extends beyond the boundaries of the health-care professions.

Editors Note: Part II will present the arguments for disclosure, including a discussion of the limitation of freedom on grounds of self-interest; the problem of the benevolent lie; triple jeopardy for the nurse; and the conclusion. It will appear in the next issue.

## NOTES

1. A number of persons contributed to this paper in various stages of its development through ongoing conversations with me. I wish to thank in particular certain of my colleagues at Michael Reese School of Nursing--Catherine Duffy, Robyn Anzalas, Bette Case, Karen Burniston, Judy Dishno and Elaine Yarling. I wish to thank also Jo Ann Ashley and Carol Eady for their helpful suggestions and Richard Paramater for his thorough critical reading of the text.

2. The statutory treatment of psychiatric records is less restrictive in Illinois. It does not include the discharge stipulation. However, we are concerned here only with the terminal medical patient.

3. Even then, the extent of information which the physician is legally required to disclose is determined, in most cases, not by the principle of what is required for the informed self-determination of the patient, but by the very different principle of customary medical practice in the community.

4. I would like to acknowledge the generous assistance of William H. Roach, Assistant Vice-President, Legal Affairs at Rush-Presbyterian-St. Lukes Medical Center for reviewing this paper with special attention to its legal analysis and making several very helpful observations.

5. This was written prior to the revision of the Illinois law.

6. George J. Annas. The Rights of Hospital Patients, New York: Avon, 1975, p. 116-118.

7. This point, which is discussed systematically later on, is here being anticipated in order to clarify the significance of the question of scope.

8. Having introduced the professional dimension here in addition to the legal and moral dimensions, a comment on the relocation of these three dimensions of nursing practice is necessary. These three factors stand in a relation of mutual influence with respect to their bearing upon rules for practice. Professional precepts are usually based upon legal and moral considerations, as well as upon ordinary and accepted practice. Conversely, laws are usually formulated on the basis of moral and professional standards, and customary practice. Over the long run, however, moral considerations are, or ought to be, determinative of the other two.

9. See "Selective Readings" on the question of patients' rights to information regarding their care which is appended to Part II.

10. Having introduced the professional dimension here in addition to the legal and moral dimensions, a comment on the relation of these three dimensions of nursing practice is necessary. These three factors stand in a relation of mutual influence with respect to their bearing upon rules for practice. Professional precepts are usually based upon legal and moral considerations, as well as upon ordinary and accepted practice. Conversely, laws are usually formulated on the basis of moral and professional standards, and customary practice. Over the long run, however, moral considerations are, or ought to be, determinative of the other two.

11. See "Selected Readings" on the question of patients' rights to information regarding their care which is appended (next issue).

12. It is possible to advance a psychological argument that the patient did not really want to know, but in this case the evidence lies in the other direction. At any rate, for the sake of simplifying the discussion, let us assume that she really did want to know.

13. We can not be absolutely certain that the physician would have maintained his position if the patient had asked him directly, but on the basis of the head nurse's past experience with him, it is probably safe to assume that he would have. Again, for the sake of simplifying the discussion, let us assume this.

14. Op. Cit. Annas.

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# ETHICAL ANALYSIS OF A NURSING PROBLEM: THE SCOPE OF NURSING PRACTICE IN DISCLOSING THE TRUTH TO TERMINAL PATIENTS

An Inquiry directed to the National Joint Practice Commission
of the AMA and the ANA

PART II

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## ARGUMENTS FOR DISCLOSURE

### Limiting Freedom on Grounds of Self-Interest

Given the assumption that the decision to disclose is essentially a moral decision subject to discussion in a wider community of moral discourse let us review some of the moral arguments in support of the position that the terminal patient who request information about his condition ought to be told. It is important, from the perspective of the nurse, to delineate these arguments with care, because the nurse is so often entangled in the moral dilemmas which such situations create.

First, it must be recognized that denying a terminal patient information about his condition is equivalent to denying that person the freedom of self-determination with respect to a fully informed encounter with the ultimate and final experience of human existence. The fact that this information is withheld in the name of the patient's self-interest does not abrogate the moral issue. One of the central issues involved here is precisely the question of whether it is ever justifiable to abridge the freedom of self-determination of any competnet person in the name of that person's self interest. We routinely abridge the freedom of certain persons in the name of the public interest, e.g. criminals, and we limit the freedom of children for their own protection, but the abridgment of competent adult's freedom in the name of that person's own self interest is quite a different matter. It is difficult to reconcile this abridgement with the principles of the autonomy and the dignity of each individual which are the most basic and widely accepted premises of our common moral life.

The dangers of abridging the freedom of self-determination on grounds of self-interest are evident if one recalls that this was the enlightened classical argument for the justification of slavery. Slavery was thought to be in the best interest of slaves because they also were regarded as incapable of using their freedom in their own best interest. To draw upon history again, it was this same kind of reasoning which the Medieval Church appealed to as a justification for keeping the Bible chained to the altar. The common person was thought to be incapable of understanding and managing the information contained therein. Therefore, it was judged to be in the best interest of the laity to limit its freedom of access to that information and disclose only what seemed to be in its best interest to know. This argument from history does not hinge upon the assumption that every free and informed man has always acted wisely. It is based, rather, upon the assumption that man's potential for dignity depends on his freedom and autonomy, and that it cannot be realized through an externally imposed security. One of the paradoxes of the human condition is that human freedom is the basis of both virtue and vice, wisdom and foolishness, dignity and degradation, strength and weakness. We cannot protect man from vice, foolishness, degradation and weakness by limiting his freedom, without also circumscribing his potential for virtue, wisdom, dignity, and strength. The abridgment of a person's freedom of self-determination, even in the name of his self-interest, is inseparable from the abridgment of that person's humanity. Consequently, refusing to answer the dying person's question about his condition is an ironic act of dehumanization. In our fear that he will be weak, we refuse him the opportunity to be courageous.

## The Problem of the Benevolent Lie

A second major moral issue involved in this question is that of the benevolent lie. Let us review the considerations in this situation which gives rise to the issue of lying. The issue does not arise unless the patient is requesting information. The position has already been taken that a terminal patient has no obligation to know about his condition if he does not want to know. So, if he is not requesting information, no one is faced with the problem of whether or not to lie to him. If he does want to know, and is requesting the information, then the issue arises. Whoever has the competence to provide the information and is presented with the request for it is confronted with a moral problem. The patient in this situation was indeed asking about her condition, and therein lies the making of the lie. Once the patient asks, there is no alternative to either an honest answer or a direct lie. Is it, then, or is it not, justifiable to lie from a benevolent motive to a patient in this situation? It is not--for the following reasons.

Lying to the patient seriously undermines the patient-professional relationship. Trust has traditionally been considered to be an essential ingredient in a therapeutically sound relationship between a patient a physician or a nurse. There has, however, been a steadily increasing erosion of that trust in recent years. The reasons for this are many and complex, but one of the contributing causes is the growing public awareness of the practice of lying to terminal patients about their situation. The fact that this lack of candor is thought by the professional to be in the interest of the individual patient makes no difference in the long run in terms of the overall effect it has upon the integrity of the patient-professional relationship in general. Lying, whatever the motive, trades on trust and truth. It can succeed only where truth is the norm. Only when the person who speaking is regarded as trustworthy and truthful can he succeed in lying. Each lie trades on and diminishes the credibility of every truth. Consequently, the practice of lying to terminal patients has made even the truth suspect. When a patient with a possibly malignant tumor is told after surgery, "It wasn't malignant" or "We got it all," he frequently is not assured. An experienced nurse, with very traditional ideas about the doctor-patient relationship, once told me after she had surgery for a suspicious tumor that she was told that everything was all right, but that she did not really believe it until at her insistence, she was shown the lab reports. In spite of, or perhaps because of, her traditional view that it is best for the doctor to decide how much the patients should be told, her distrust was irrepressible. For her, the truth was not credible without proof. This compound dilemma, which the practice of lying to terminal patients has created, was inevitable. The end result of lying even from a benevolent motive, is always the destruction of trust and the undermining of the very conditions of communication upon which meaningful human relationships depend. Lying to the patient from a benevolent motive is, therefore, morally unacceptable, not only because it necessarily damages the trust that many patients place in the professionals who care for them, but more generally, because it advertently erodes the foundation of the human community by treating language not as a gift for the purpose of communication, but as a means of exercising paternalistic, if benevolent, dominion over other persons.

## Triple Jeopardy for the Nurse

For many nurses there is another compelling reason why lying to the terminal patient is morally problematic. Under the frequently prevailing circumstances wherein the disclosure of diagnostic and prognostic information is considered to be the prerogative of the physician, the nurse is often placed in double moral jeopardy. Let us posit the following set of circumstances to illustrate the nature of this double jeopardy in which she may find herself. If she holds views roughly similar to those outlined above (regarding the limitation of freedom on the basis of self-interest and the practice of lying from a benevolent motive); and, if she is caring for a terminal patient who is persistently seeking information about his condition; and, if the physician has chosen, out of a desire to protect the patient, to assure the patient that all is well; and, if he has ordered those caring for the patient to withhold all information to the contrary; then she is placed in the position not only of having to lie to the patient, but also of having to lie _for_ the physician. This involves a morally significant shift in the reason for the lie. While the physician may appeal to benevolence as a justification for lying to the patient, the nurse, if she understands the requirements of benevolence differently, is placed in the position of having to lie, if she does so, not out of benevolence, but out of loyalty to the physician, or out of deference to institutional policy, or perhaps just as commonly, out of self-interest concern for the security of her job. Therefore, the nurse in such a situation is in double moral jeopardy if she chooses to follow the physician's orders, because she must not only lie to the patient, but must do so for reasons that are not morally acceptable to her.

As difficult as this situation is for the nurse, there is yet another factor which makes it even worse, creating, if you will, triple jeopardy. This factor is the amount of interaction which the nurse has with the patient compared with that of the physician. Typically, the nurse spends much more time with the patient than the physician does--especially the terminal patient. Therefore, while the physician may prescribe the terms of interaction with the patient, assure the patient initially that there is nothing to be concerned about, and see the patient for a few minutes each morning, it is the nurse who, by and large, must live day after day with the deception. She must keep the benevolent lie alive while the patient dies, devising extemporaneous, credible answers to the patient's ongoing questions about this pain and that symptom. The physician's delegation of responsibility for the nurturing of the benevolent lie is a very problematic action from a moral point of view. It places the nurse in the position of being the executor of what is, from a moral point of view a culpable policy. Given the nurse's necessarily frequent interaction with the patient, the only possible way to avoid this unacceptable situation is to be honest with the patient. Thus, disclosure becomes absolutely necessary on several grounds.

It can be argued that the nurse could be protected from having to maintain the benevolent lie for the physician by an institutional policy or a rule of professional protocol which would dictate that only physicians may disclose such information to patients. This would permit the nurse to say "I'm sorry, but you will have to ask the doctor about that." This policy, however, is predicated upon three implicit and unacceptable premises which have already been rejected, the first being that the decision to disclose or conceal is the prerogative of the physician because of his medical expertise. The second false premise embedded in such a policy is that moral responsibility is abrogated by institutional policy. If the patient has a right to know, the moral obligation of the nurse to inform, given certain conditions which are discussed later, is not in any way affected by institutional policies or professional protocol. Moral rights and obligations are not subject to creation, definition, or extinction by institutional policy. A third premise for such a policy is that nurses generally are incompetent to inform such patients of their condition. It may well be that a particular nurse will lack the medical and/or psychosocial competence to inform a patient, but there is no reason to assume that, on balance, the requisite competence for this task is any more likely to be lacking in the nurse than in the physician. Another word on this later. At any rate, the question we have been propounding all along is the question of what is proper to the practice of nursing on the basis of an independent and competent nursing judgement.

## CONCLUSION

### Rights and Obligations of Disclosure

The chief concern of this analysis is the question of who has the right and the obligation to disclose sensitive information to the terminal patient. As we move to a direct discussion of this question, two fundamental distinctions once again come into play: The distinction between rights and obligations, and the distinction within each of these, between morality and legality. It has been argued that the patient has a moral, but not a legal, right to know the truth about his condition. Given the patient's desire and moral right to know his condition, what are the moral, legal, and professional rights and obligations of the nurse (and the physician) to disclose such information?

The answer is implicit in the preceding discussion, but let us spell it out. The moral right is determined by the following three factors: The medical knowledge and psychosocial skill to make the disclosure competently, collaboration and communication with one's colleagues, and rapport with the patient: competence, collaboration and rapport.

Competence for the task includes medical knowledge of the disease and psychosocial skills in communication. The nurse's knowledge of the disease should be sufficient to enable her accurately to describe the disease process and possible treatments and consequences to the patient's satisfaction. If she judges herself deficient for this task, she may consult with another nurse or a physician, she may do some research on her own, or she may explain to the patient that she thinks someone else can better answer his question, and then refer the patient to someone who can and will respond to the question honestly and competently. She is responsible for assessing her own competence and acting accordingly. If the physician is more likely to have an adequate knowledge of the disease process, the nurse is more likely to possess adequate communication skills. Nursing education curriculums generally contain major components on such skills. Medical education curriculums seldom do. More to the point, however, is the fact that the medical and nursing professions have evolved in such a way that it is now possible to say, without much distortion of the actual situation, that, in general, physicians specialize in diseases and nurses specialize in patients. This may not particularly please either physicians or nurses (or it may), but both would be hard pressed to deny that this is the way it has come to be. When not much more can be done about a disease, a great deal more can frequently be done for the patient. Characteristically, it is the nurse who does it. On balance, then, the sensitive nurse is, by virtue of her experience, as likely as the physician to possess the requisite competence for disclosing such information. Certainly, neither the physician nor the nurse is morally entitled to perform any professional task which she is not reasonably competent to do. Moreover, every professional who judges himself or herself competent to perform a certain task, and proceeds with it, stands accountable for that action.

Collaboration and communication among those responsible for a patient's care are essential to safe, efficient, high quality care. This principle is basic to the integrity of a health care team. It applies fully here. Before making a response, the nurse who is questioned by a terminal patient about his condition ought to consult with the physician if there has been no prior discussion of the matter. The physician may have some insight into how the disclosure might best be made. The physician has a similar responsibility with respect to the nurse. It might, in some cases, be a good practice for the nurse and the physician to discuss the situation with the patient together. Under ordinary circumstances, the nurse and the physician should consult with each other before talking to the patient, and, under all circumstances, each should keep the other informed of action already taken.

Rapport between the patient and the professional may be rooted in a variety of experiences and circumstances. In the case of the physician, it may be rooted in a long-standing relationship as the patient's personal physician; in the case of the nurse, it may be in her continued, caring presence during the illness in question. Whatever the circumstances, openness to and concern for the patient as a moral being as well as a medical subject, are of primary importance.

The importance of rapport with the patient cannot be over estimated as a criterion of the right of anyone to inform the terminal patient of his condition. The process of death and dying is a primal experience and learningof the imminence of death constitutes an intimate moment of human existence. From whom the patient hears the news of his mortal illness is a matter of great importance. The bearing of that news should not be regarded as primarily a technological task of disclosing scientific information. It is an act which transforms clinical facts into bits of personal history. It creates a sacred moment of human communion between patient and professional and the bearer of the news must be capable of entering into the intimacy and the burden of the moment with the patient.

The question of who has a rapport with the patient which will enable this kind of sharing is usually best answered by the patient. It is a serious oversight to assume that his decision to ask a particular person is without significant meaning. The patient who knows or suspects that there is a definite possibility of serious problems, and who is asking questions, has probably carefully selected, consciously or unconsciously, the person of whom he asks the fateful question. The decision of the patient to ask questions of a particular person is of such importance that it should be, as a general rule, the overriding consideration about who should inform the patient. If it happens to be a family member or friend, the rule should still hold. The important point to keep in view is that the telling of the news is essentially a sacral rather than a technological task, and it is its sacral character which should be preserved. Any number of people will possess the technological expertise to do the job, but there may be only one person who can perform this essentially priestly function satisfactorily for a particular patient. If it happens to be someone without the necessary medical knowledge to provide detailed explanations of the situation at the moment of disclosure, that person may consult with the physician or the nurse to get as much information in hand as possible. In fact, it may be wise to have a knowledgeable person on standby in case the patient wants a fuller explanation immediately. Whatever the procedure, the overriding concern ought to be for the self-determination of the patient not only with respect to the source of that knowledge. This is right in and of itself, for it recognizes the sacral nature of the task and provides the patient with the maximum possible support.

In conclusion, if the nurse has the appropriate competence, has collaborated with her colleagues, and has a rapport with the patient which has caused the patient to ask her about his condition, her moral right to make the disclosure is indisputable, given the patient's desire and moral right to know. However, establishing the moral right of the nurse to make such a disclosure under the conditions specified must be distinguished from establishing moral obligation or responsibility for the same act. Rights and obligations are, as already noted, very different things, one may have a right to do something without being obligated to do it. As previously noted, the right (or freedom) of the patient to certain information if he desires it, is quite different from the obligation (or requirement) to receive the information if he does not desire it. In other situations, however, the right and the obligation to do something may be related in such a way that the right automatically entails the obligation. Such is the case with the nurse (or the physician) disclosing information to the patient under the conditions specified. Unless all those conditions--competence, collaboration, and rapport--are present, the moral right of the nurse (or the physician) is dubious, but if they are all present, then both the moral right and the moral obligation arise from those conditions. For instance, given the presence of competence and collaboration, there is no clear moral right to disclose unless the patient asks; but when the patient does ask, thereby suggesting the requisite rapport, the obligation to disclose arises along with the right to disclose. Both are rooted in the patient's exercise of his right to know.

Therefore, given these conditions--competence, collaboration, rapport--it must be concluded that *the nurse has both the moral right and the moral obligation to respond honestly to the question of the terminal patient about his condition*.

This being so, there remains the question of the *legal* rights and obligations of the nurse in such a situation. The preceding analysis indicates that *the nurse who responds honestly to the question of the terminal patient about his condition, with accurate information and sensitivity (competence), within a context of trust and support (rapport), and with the full knowledge of her colleagues (collaboration), is well within her legal rights under the law in most states.* This conclusion holds even when the family, the physician and other nurses may disagree.

There are three essential premises upon which the previous conclusions depend. The first is that the patient has a moral right to know. The second is that legal rights and obligations ought to be a reflection of moral rights and obligations. (It is for this reason that so much of the preceding discussion is given over to ethical analysis.) The third is that the legal situation of the nurse is sufficiently ambiguous that it is open to precedent-setting interpretation. Consequently, even the legal question turns out to be fundamentally moral in nature. Its resolution depends upon a determination of the patient's moral right to the information requested and upon the priorities assigned to the conflicting commitments of the nurse. Given the stated concern of the National Joint Practice Commission for the ethical accountability of health care practitioners in a context of collaborative care for the patient, the Commission is an ideal forum for debate and decision on the issue.

The question of the legal *obligation* of the nurse is another matter. *There can be no legal obligation on the part of the nurse (or the physician) to disclose as long as there is no legal right on the part of the patient to know*. The patient *should* have a legal right to know, because he has a moral right, but in fact, he does not. The absence of this legal right is a scandalous state of affairs.

As for professional rights and obligations, if there be such things over and above moral and legal considerations, they are derived from moral and legal rules and from ordinary and accepted practice. Given that there is a moral obligation and a legal right (although not a legal obligation) to disclose, a *professional right and obligation on the part of the nurse is also* clearly present.

The foregoing discussion of rights and obligations may be represented diagrammatically as follows:

> This is not to say that the physician, in similar circumstances, does not have the same rights and obligations. There is no suggestion here that the nurse does have or should have the exclusive right and obligation of disclosure in such a situation. The conclusion is, rather, that the act of disclosing diagnostic and prognostic information to the terminal patient, upon request from the patient, is not *exclusively*

an act of the practice of medicine, but is also properly an act of the practice of nursing. It is an overlapping function within the practice of nursing and medicine. However, unlike certain other overlapping functions, when conflict arises over the issue of disclosure, it cannot be resolved on clinical grounds. It is a moral question requiring moral, not clinical, analysis. It requires a moral decision.

An expression of opinion from the Commission is hereby requested.

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## Chapter 46

# THE MORAL SITUATION IN NURSING

Catherine P. Murphy

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Chapter 46

# THE MORAL SITUATION IN NURSING

Catherine P. Murphy

## CRITERION FOR A MORAL SITUATION

In order to have a moral situation, Barry Chazan[5] holds that several criteria must be met. First, the individual must be faced with a human confrontation or a conflict between human needs or the welfare of others and the need to choose between alternative behaviors or actions. Second, the choice made must be guided by moral principles that are universal prescriptions for behavior, embodying some theory of justification. Third, the choice must be guided by a process of weighing reasons, and the decision must be freely and consciously chosen. Last, this choice is affected by feelings brought by the individual, and caused by the situation, and the particular context of the situation.

Nurses meet the first criterion, for they are constantly confronted with conflict between human needs in which they are faced with the dilemma of choosing alternative actions. For example, nurses are faced with all the inherent moral quandaries associated with life and death situations, truth telling and informal consent; behavior control and drug research on human subjects; and when their professional services become a scarce commodity, they must practice triage in the allocation of care in understaffed situations. Because of the very nature of their work, nurses in health care institutions are constantly confronted with moral conflict. Since nursing decisions are concerned with human life and they directly affect the welfare of other human beings, they ought to be measured by ethical or moral standards.

The second criterion for the moral situation focuses our attention on the role of moral principles in guiding choices to be made. Philosopher R.M. Hare advises us that a moral principle is a statement that conveys some directive or prescriptive force[18]. He emphasizes a moral principle as a weaker form of a prescriptive statement, because it should not directly cause or command certain behavior but rather suggest or propose certain behavior that the agent himself chooses in guiding his actions. Since the moral principle should not be a directive made by an authority figure, it becomes then an internal suggestion that the agent himself uses in guiding his behavior.

The nurse's role involves inherent conflict between two moral principles or normative components of her role. First, a nurse is morally obligated to recognize the right of the patient as an individual, or to put it in nursing language, she has a commitment to meet the individual needs of her patient. On the other hand, as an employee in a health care institution, the nurse is subordinate to the administration and, hence, must uphold the utilitarian goals of the institution: the greatest good for the greatest number. The consequence is that a patient must be ready to sacrifice his individual rights or needs for the greater good of all other patients in the institution.

Since hospital administration has for all too long controlled both the educational and practice settings for nurses, they have also controlled the socialization process in nursing. To make sure that their utilitarian goals were not interfered with by dissension, hospitals saw to it that nurses received "proper" moral indoctrination by stressing the virtues of loyalty, duty, subservience, and blind obedience to authority.

The nursing values of unquestioning obedience to authority and dedication to duty that were rooted in the profession's military and religious tradition have led to the "ours is not to reason why" approach to nursing practice. As late as 1973, the American Nurses' Association president, Rosamond Gabrielson, noted that we were still struggling with our "born in the Church--bred in the Army" authoritarian heritage[13]. Nursing's Victorian values of unthinking obedience to authority figures and fixed rules and regulations are dysfunctional for the newly defined role of the nurse as a morally responsible agent who is an advocate for the patient and guardian of his rights. Each moral situation requires an independent moral judgement on the part of a moral agent, and a nurse must be able to engage in moral reasoning that is based on moral values and principles that are separate from institutional norms and authority. Nursing's antiquated values and moral principles must be examined in the light of modern standards, for the concept of professional autonomy is lost in an environment governed by rigid authoritarianism. Autonomous behavior on the part of a professional nurse should be autonomy within the context of disciplined moral reasoning and action. Nurses need to direct their use of newfound freedom with real values and responsible moral judgements.

Since Chazan's third criterion of weighing choices and having freedom to choose among alternatives is closely tied to his fourth criterion in the moral situation in nursing, it seems appropriate to consider them together. While an increasing number of professional nurses practice outside of hospitals, nursing by and large is still practiced in hospitals. For this reason, my consideration of situational contexts in the moral situation is limited to this type of setting.

## CONTEXT OF THE MORAL SITUATION

The particular context or moral atmosphere in which the moral situation takes place in nursing is such that it limits a nurse's ability to perform and make moral decisions. Organizational theorist Herbert Simon maintains that in order to analyze the effect of environment on the decision-making process, one must study the organization's "anatomy" and "physiology"[38]. The anatomy of an organization can be found in the distribution and allocation of decision-making functions, while its physiology can be viewed by analyzing the process whereby an organization influences individual members by supplying their decisions with organizational premises. Organizations control centrality of decision-making by preventing those low in rank from being able to weight competing considerations and by requiring that employees accept conclusions reached by members higher in organizational rank. This control is accomplished by imposing general rules to limit discretion or by actually taking the decision-making function out of the hands of the employee. The organization further structures the employee's decision-making environment by control of the communication system and by internalizing values and decision rules through training and indoctrination[32].

Hospital physicians are in a staff position and not usually employed or subordinated to administrative authority. Even though outside of the administrative chain of command, they have authority to issue orders directly to nurses. Nursing staff are in a line position, which makes them responsible to the administrative hierarchy as well to the physicians. This dual chain of command creates conflict and severely limits the decision-making role of hospital nurses because they are subordinated to two lines of authority at one time. A range of empirical studies shows that physicians are central to the decision-making process and nurses are relegated to the role of implementing their decisions, for in effect, the physician's orders determine the framework for all the care given [8,14,15,22,29].

The network of communication in the hospital hierarchy allows the physician to move freely throughout the institution while the nurse must communicate through "proper" bureaucratic channels. The pattern of communication between nurses and physicians has been portrayed as the nurse-doctor game by phychiatrist Leonard Stein[39]. The rules of the game are that the nurse must appear passive, and if she should be bold enough to offer information or recommendations, it must be done in a manner that makes it look as if it was initiated by the physician. Making a suggestion to a doctor can be equal to insulting or belittling him, and the penalties for failure to play the game can be severe.

What are the consequences of such an atmosphere and how does it affect the attitudes of nurses and the quality of the nurse-patient relationship? A host of studies focusing on the dynamics of ethical decision making, such as those by Lawrence Kohlberg and others, clearly shows that the moral reasoning of an individual is affected by the moral atmosphere[25]. Studies by nurse researchers Bueker, Jarratt, Simms, Harrington and Theis support this finding, since they conclude that the social organization of the hospital affects the value orientation and role performance of the nurse[4,19,22,37]. In one recent study on the moral reasoning of nurses, the findings suggest that most of the participants were at a conventional level of reasoning that stresses obedience authority and the need for harmonious relationships with institutions and authority figures even when patients' rights were being violated[33].

## VALUES NURSES BRING TO THE MORAL SITUATION

In addition to the situational factors that limit conscious, freely chosen alternatives for action and the ways in which the context of the moral situation can affect the manner in which a nurse values or chooses certain behaviors, what are the attitudes, values, and predispositions that nurses bring to the moral situation that also affect their choices? Emotional needs, internalization of role stereotype, social class, educational training, and sex affect the attitudes and behavior of nurses as organizational employees. Dominant-submissive patterns of behavior are frequently seen in the personalities of employees in bureaucratic organizations. Sociologists

Bensman and Rosenberg believe that this pattern of behavior is a factor in attracting employees to begin with, and it is subsequently reinforced with continued employment, for the precise and inflexible rules of organizations offer a sense of psychological security for many employees[3].

Some researchers suggest that a theory of match fits an individual's mode of moral reasoning or ideology to his working environment[11,20,26]. Robert Hogan's research on moral reasoning claims that individuals are self-selected to occupations on the basis of their personality and moral reasoning. He found that individuals who place high value on rules and codified procedures in regulating human affairs were drawn to occupations that preserved and defended conventional social institutions, while individuals who considered rules a hinderence were drawn to occupations that promoted social change[20].

Moral reasoning and related personality characteristics may be a preselection factor in choosing nursing as a career. The sex-linked nurse stereotype that embodies obedience, caring, warmth, and nurturance has been the image that is constantly reinforced in books, games, and the media[10,35,36]. In the past, studies have indicated that high school and college students who reject nursing as a career do not feel that nursing offers opportunity for self-realization, originality, or creativity[12,28]. Claire Fagin contends that this image of nursing often discourages "the career minded, more aggressive women from choosing nursing"[10]. Moral reasoning may also affect student success in a school of nursing. Research shows that there is a strong relationship between selectivity in recruitment and decrease in need for subsequent employee control in organizations. If personalities are shaped to fit organizational roles, there is much less need to socialize and control employee performance[6].

The educational environment in nursing has been portrayed as being rigid and authoritarian, and it is said to reflect teaching styles that impart subservience and appeal to authority for approval[2,16,21,31,34]. The student-teacher relationship has been compared to that of recruit and drill sergeant in the military, with faculty rigidity inhibiting independent action on the part of the student[39]. Research findings indicate that nursing students perceived that there was an absence of justice in their educational environment, that they did not feel free to express their opinions, and that faculty failed to treat them as autonomous individuals[34,40,41]. In a longitudinal study of nursing students, Olesen and Whittaker found that if nursing students did not conform and reflect the nursing value of "modesty" and "humility", they were branded as "overconfident" and considered "potentially unsafe." The dropout students who scored higher on nonauthoritarianism than the more successful remaining students were unable or unwilling to cultivate the required demeanor[34]. It seems that faculty in nursing education who act as recruiting agents for the profession place high emphasis on the conformist attitudes of the profession and, consequently, weed out students whose values do not match the conventional values of the educational and practice environments.

Since the traditional role of the nurse has been one of subservience and unquestioning loyalty and obedience to authority, it only stands to reason the conventional mode of moral reasoning is functional for the role that the nurse has been forced to play in the health care system. Nursing literature and research suggest that there is a selection bias in nursing administration in favor of nurses who are subservient and loyal to the institution and its authority figures[1,6,17,27,30,43], and there is a strong possibility that mode of moral reasoning may be functional for achieving success in nursing practice.

Nursing has been predominantly a female profession, and recent attention has focused on the difficulties encountered by nurses as members of a female profession. Researchers in one study on moral reasoning suggested that attainment of autonomous morality was more difficult for women because it involved conflict with the traditionally defined feminine role of dependence and irresponsibility[17]. Nurse researcher Cleland holds that nursing's lack of autonomy is directly attributed to the social position of women in society and is a result of the socialization process of females[7]. Sociologist Strauss maintains that the practice of nursing reflects the feminine virtues of "responsibility, motherliness, femininity, purity, service, and efficient housekeeping, while it has omitted the 'political (equal rights) reformer' themes"[42].

## NEED TO CHANGE THE MORAL SITUATION IN NURSING

I maintain that it is necessary to have nurses engage in moral reasoning that is separate from institutional norms and authority. If a nurse is oriented toward the utilitarian moral principles of the institution, she is not capable of reducing the welfare and claims of a group of people to the welfare and claims of patients as individuals. When faced with a situation of moral conflict, she will weigh alternative solutions in terms of the consequences for the social order of the group or institution rather than in terms of justice to the individual patient. Justice becomes a principle for social order rather than for personal moral choice, and the consequence of being unable to engage in moral reasoning that weighs competing claims of each individual in moral situations results in unthinking obedience that renders a nurse helpless when faced by conflicts of duty[25]. The nurse, then, submits to the edict of superiors and the fixed rules and regulations of the institution. The "collective morality" of this kind of reasoning has been destructive to nurses' individual morality, for it has led to loss of personal integrity and accountability and has permitted nurses to absolve themselves of misdeeds by placing blame and responsibility on others. Since this type of reasoning is directed toward maintaining rules and the existing social order for its own sake, it cannot provide rational guides to social change and the creation of new norms in the health care system. Nurses cannot be expected to be agents of social change if they do not go beyond this level of reasoning.

While it would not be wise to do away completely with all rules and authority in nursing, there is a need to develop a more reflective and selective approach toward dealing with them. Nurses have had much responsibility with very little authority and virtually no accountability. A crisis of authority is under way in society and health care today, and nursing needs to begin to think about the basic nature and function of authority itself. We must begin to reconsider the whole meaning of authority in order to develop a new locus of authority, namely, authority that stems from the patient and not

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the health care hierarchy. Nurses must begin to think of their moral and political authority as coming from the client and not from the health care bureaucracy.

## WAYS TO IMPROVE THE MORAL SITUATION IN NURSING

Throughout history the nurse has been the humanist in health care. Her role as the only logical advocate for the patient and guardian of his rights must be made legitimate. In order to prepare the nurse for the role of patient advocate, I propose a marriage between nursing and philosophy to increase the nurse's knowledge and expertise in ethical decision making. Nurses must be engaged in moral thinking, and they must be guided through, and made aware of, the moral situation and its components[5]. We must become more and more aware of the forces that shape our values, and we must look at the values of our patients as well as our employers.

In order to prepare nurses to be moral agents, we must create educational and service environments that allow nurses to act as moral agents. Studies concerned with the moral atmosphere of educational environments have indicated that students respond best to a combination of moral reasoning, moral action, and institutional rules as a relatively unified whole in relation to their mode of moral reasoning[23]. The potential of a moral atmosphere to stimulate moral reasoning depends upon its environmental level of justice and the extent to which it provides role-taking opportunities by allowing individuals to share in responsibilities and the decision-making process[24]. The educational environment in nursing must have a high level of institutional justice that is based on democracy and fairness and recognizes the dignity and rights of the learner. Students should be encouraged to enhance their role-taking abilities by becoming actively involved in the social and moral functioning of their school and practice environments. In the teaching of ethics and in confronting situations that require ethical reasoning in nursing education, the following criteria are necessary for stimulation of cognitive conflict and moral reasoning: There must be exposure to situations that present moral conflict and contradiction for the learner's current moral structure; interchange and free dialogue between teacher and student; and moral reflection that involves identity questioning, commitment, and consistency between moral reasoning and action[24].

The current practices in nursing service, wherein value decisions are formulated by those in authority and nurse subordinates perform the technical aspects of labor with unquestioning obedience and lack of responsibility for consequences of actions, must be abandoned.

Service agencies must therefore:

1. Change the justice structure of their institutions so that nurses can share in decision making and responsibility and be free to make moral choices, thereby creating a moral atmosphere where there is commitment and consistency between moral reasoning and action.

2. Institute courses in ethical reasoning through in-service education for all nurses.

3. Expose new graduates to role models and working environments that reflect and support principled, autonomous moral reasoning, so that cognitive awareness of moral principles can be developed into a commitment to their ethical application in the practice of nursing.

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# THE NURSE: WHEN ROLES AND RULES CONFLICT

Andrew Jameton

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# THE NURSE: WHEN ROLES AND RULES CONFLICT

by Andrew Jameton

Most bioethics teaching in nursing has consisted in simply extending the teaching of standard medical ethics issues to a new audience--nurses. This is a mistake. The practice of nursing gives rise to a variety of ethical problems either unique to the profession or significantly modified by it.

Some of these problems are complex and philosophically fundamental. The professional nurse performs an unusual variety of roles--patient advocate, aide to the medical profession, hospital staff worker or administrator--as well as nursing professional. This combination of roles, very different from the physician's role, raises a host of ethical problems related to autonomy, coercion, role conflict, and personal identity. Moreover, nursing theory is a unique combination of sociological, biological and psychological theory. Nursing attempts a "unified science" approach to patient care combined with a sophisticated analysis of the professional/patient relationship. This approach lays the foundations for an integrated conception of an ethics of health and health sciences.

Besides being philosophically important, the ethical problems of nursing are fundamental to understanding the broad ethical issues of health care institutions. As Thomas McKeown argued in The Role of Medicine: Dream, Mirage or Nemesis (London: Nuffield Provincial Hospital Trust, 1976), health care institutions play a minor role in overall improvement of human health. It is reasonable to conclude that their main function is that of care and comfort of the sick. Since this is a paradigmatic nursing function, the nurse is the central figure in health care, not the physician.

A philosophical understanding of the ethical issues of nursing practice thus tends to approach more closely the core of understanding health and health science than an understanding of medical ethics. Some of the ethical issues that arise most obviously in nursing are the following.

Principled action in the face of conflict with others or threat to personal interest is an ancient ethical problem. Their subordinate position in the health care hierarchy and their complex role make this a common conflict for nurses. This conflict wears many faces. It appears sometimes as a question about personal power--how much can I change things? Sometimes it appears as a conflict between altruism and self-interest--will I lose my job if I take a stand on this issue? And sometimes, it appears to be a question of expertise and authority in moral judgement--shall I stick with the way I see things or trust the judgement of others? For example, some patients appear repeatedly in the emergency room suffering from overdoses of drugs as a result of suicide attempts. The physician may insist on resuscitation while the nurse feels that it is a waste of effort and an insult to the patient. How shall this disagreement be resolved? Or, the physician still in the hospital tells the nurse, "If any of my patients ask for me, I have just left the hospital." Should the nurse lie on behalf of the physician?

Many conflicts arise from the nurse's complex role, so that they can be grouped under the heading of the "nurse in the middle" problem. The nurse often appears to be in the position of having great responsibilities, required to have many skills and yet in possession of few decision powers. In what direction should nurses seek to resolve this problem--toward expressing their views more, obtaining a vote on committees, running the show, knowing their own view, or finding a clear framework for accountability?

Nurses have an important role in patient education, and have traditionally been regarded as a "reflecting and refracting medium" for medical advice. Many strictures on what nurses may tell patients are bureaucratically awkward and professionally demeaning to them in their role as patient educators. If the physician has not told a patient the whole story, what is the nurse's responsibility to provide fuller disclosure? Would it be proper for a nurse to discourage a patient from a course of treatment which the patient's physician recommends?

Issues of the right to health care and the responsibility for the care of individual health come to a focus on the question of appropriate treatment of irresponsible patients and patients responsible for self-abuse or neglect of treatment regimens. Since nurses actually implement many physician-ordered procedures, they more often face this problem at the point of conflict. To what extent is it proper to attempt consciously to control the patient's behavior so as to encourage sound health practices, or to strengthen the patient's trust or hope in order to ease health management?

What is the appropriate response to the angry, demanding or unappreciative patient? Should nurses ever express feelings of hostility toward patients? These conflicts raise questions of self-assertion and of the extent to which personal roles can be used to realize personal objectives.

Different conceptions of health affect the nature of nursing practice. The unified science theory of nursing, combined with a broad conception of health, raises the question of how deeply and extensively health professionals should involve themselves in the lives of their patients more sharply than does medicine, which is mainly committed to a narrowly biological conception of health.

The disparity in income, power to make decisions, and prestige between the nursing and medical professions is a source of resentment in nurses and conflict between the professions. Is this disparity justifiable; is it just? To what extent is the division of labor between physicians and nurses a result of a rational distribution of labor and to what extent is it merely a product of traditional sex roles? Feminist analyses of autonomy and self-concept can help to explain and to change patterns of decision-making in health care. And by encouraging nurses to express themselves more confidently on ethical issues, bioethics courses can play a small part in correcting the imbalance in decision-making power between the professions.

"Who's to say?" or "Who should make this decision?" is a classical ethical question arising frequently in nursing. Whose job should it be to tell bad news, to obtain informed consent to therapy, to explain the goals and nature of procedures? Patterns of decision-making affect the overall justice and humanity of health care delivery. They affect the efficiency and rationality of the use of expertise, the feelings of workers and professionals about the use of their skills, and the kinds of roles patients can play in making decisions.

Legal and professional aspects of nursing also give rise to ethical problems. A few of them are: Nurse Practice Acts, Nursing Codes of Ethics, Nursing Malpractice, Nurse-practitioners, Midwifery, Professional vs. Technical Nursing, Right to Strike. Topics raised under these headings have medical parallels, but specific terms are differentiated by the nature of the professions: What social and political responsibilities are placed on nurses by their professional licensure? What would nursing practice acts be like if nurses could determine their nature free of accommodation to the mold already set by medicine? Who should have what skills? What relationships between professions are likely to realize a humane working environment?

Standard issues in bioethics, such as termination of care and informed consent to therapy, are of course also interesting to nurses. Even here, professional differences shift the focus of issues. In nursing, sharing bad news with the dying patient is not an issues simply of what to tell. Equally important are questions of who is to tell, and who is to tell when those whose job it is to tell aren't meeting their responsibilities.

In general, standard bioethical issues require different treatment in several respects: First, issues of responsibility and the metaphysical basis of ethics will arise more forcefully than in medical ethics. Second, issues of role, and in particular, relationships between professions and professionals arise. And third, much medical ethics discussion proceeds on the simplifying assumption that one professional is making decisions. Although this friction may work as a representation of medical decision-making, any work on ethics in nursing must recognize a multiplicity of professional agents.

Virchow once wrote: "Medicine is nothing but a social science. Politics is nothing but medicine on a large scale." Even more so in nursing. Politics and power, personal needs and goals, and rules and roles have their impact on ethical decision-making. These elements come to the fore in a study of ethics in nursing and give to it a special depth and interest.

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# THE CARE OF THE DYING PATIENT AND HIS FAMILY

Cicely M. S. Saunders

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# THE CARE OF THE DYING PATIENT AND HIS FAMILY

Cicely M. S. Saunders

The care of dying patients or terminal care, as it has come to be called, is no new thing. Few of us do more than learn from other people, and St. Christopher's has joined St. Joseph's Hospice, the Hostel of God, St. Luke's Hospital, and Marie Curie Foundation and others in trying to fill what has been a gap in the general medical services. The teaching which is represented here is based on their long experience. You are asked to forget one special place and to put the patients we discuss into your own setting, translating general principles into particular situations. All those who work with dying people are anxious that what is known already should be developed and extended and that terminal care everywhere should become so good that no one need ever ask for voluntary euthanasia.

## The Family the Unit of Care

Nothing that we do should serve to separate someone who is dying from his family. There may be moments of difficulty or even despair but it is of first importance that they should come through to the end together. The journey itself may ease the next stages for those who have to go on living afterwards.

The first meeting with more than half of our patients takes place in their own homes. This is sometimes a visit to assess the need for admission which may be arranged immediately. At other times most of the care given by the Hospice consists of visits by our Out-Patient Sister and her staff over many weeks or even months. Patients may never need admission at any time but remain at home under the care of their own doctors and district nurses.

A family doctor asked our clinic staff to visit one young woman in her forties whose pain and vomiting had become uncontrollable. We discovered later that by this time her distress was so great that not only had she attempted suicide but when she failed the family had discussed whether they should not add together all the pills in the house and try to end her life. We were not told this until a year later. Instead, she spent most of that year at home with her family, able once again to enjoy life, to cook and even to shop and to care for the three children. She overcame her fear of hospitals, attended our Out-Patients, came for one short stay to re-establish control of her vomiting and finally came in peacefully for her last few weeks. One of the things she said to us at the stage was, "The children are a year older." It was when she was dying that we were told of the despairing attempts of a year before. We asked if she had ever again demanded for her life to be ended. We were told, "Never. Not after the Sister came, because she never had any more pain." We know that this family has really begun to live once more, as her husband calls frequently at a social club at the Hospice designed for such informal "follow-up." How different it would have been if they had remembered only the bewilderment and guilt that follow a suicide or the course they had discussed. And they all needed that extra year.

We should aim to involve the family from the beginning. For example, we may be able to ask for their help in getting a patient comfortable in the bed as he first arrives, thus symbolizing their inclusion in all that happens. At other times we have to go more slowly. The fear of seeing physical distress and being able to do nothing about it, coupled with the other demands which can seem too great to meet, may often make a family withdraw from real communication with a dying patient. When one sees tensions relax, children really listen to what their father says, a wife sitting quietly reading her paper beside her husband in bed, we believe that isolation has been overcome, and that this is, perhaps, the most important result of all our efforts. This may stem as much from the informal atmosphere of a community planned for such care with the minimum of hierarchy as from the skills which relieve pain, fits, confusion or other distress. After such a coming together the final parting is far more peaceful. We see desperation fade and people come to the place where they are able to let go quietly.

We are finding in our research among bereaved families that just as most patients wish to remain in their own homes as long as they can, so families also wish to manage if only they have enough medical, nursing, and social support. The pattern of care which appears to leave the least stress and feeling of guilt in bereavement is that in which a patient is cared for at home as long as possible and admitted to hospital within a week or two of his death.

## The Control of Physical Distress

Terminal pain can be a kind of "total" pain which obliterates almost everything else from consciousness. Some of our patients have illustrated feelings of their improsonment in pain drawings. They portray a situation completely different in character from the temporary events of acute pain with which we are too apt to compare it. Even such total pain can be relieved and forgotten.

Treatment for such pain should begin with the use of any specific treatments which may be relevant. Painful infections must be treated, fractures immobilized by fixation or traction; radiotherapy and chemotherapy may still be of value. The use of steroids may also help greatly towards the relief of pain as well as of anorexia (often a particularly depressing symptom). We must also remember that such complaints as hemorrhoids (sic) and toothache hurt just as much or more when one is dying and that distractions and pleasures still give temporary forgetfulness.

There are many drugs that may be useful for moderate pain and they should be used concurrently with such treatments as are mentioned above and certainly as soon as pain becomes part of a patient's life. Relief is self perpetuating and the expectation that something will help is an important factor in pain control at a later stage. It is, however, the experience of all those who care for numbers of such patients that narcotic drugs are at present irreplaceable and can be used effectively for weeks or months. They can also be withdrawn if the need for them ceases. There will always be the small number of patients who confound the prognostications of all the doctors and enter a period of unexpected remission. Sometimes this seems to be induced by the very relief of pain itself; more often it seems to be linked with the renewed appetite and the other effects of steroid therapy. It is certainly helped by the stimulation of occupation, interest, and pleasure. Parties are an important factor in terminal care.

Constant pain, typical of terminal malignant disease, calls for constant control. Constant control calls for drugs given regularly on a schedule and at a dose level which will prevent pain from occurring at all or at least from becoming severe enough for a patient to add to it by fear and tension. Pain is the strongest antagonist to any analgesic. Once pain has been permitted to take any kind of hold it will call for a larger dose for its control. If a drug is balanced or "titrated" against a patient's need for it in such a way that it covers slightly longer than the chosen routine time it will arrive automatically before the pain has begun to move into the vicious spiral of self-perpetuation and dose increases. The patient who does not receive his analgesics regularly and who is continually having to ask for them is reminded each time of his dependence upon the drug and upon the people who give it to him. Most pain can be controlled on such a regime by narcotics given orally. We do not find that we have to increase doses continually or to push them up to high levels, except in a minority of patients, and never have we lost control. Many of our patients receive narcotics for weeks and months, at home or in the Hospice, and we have not found that the drugs become ineffective nor that patients become psychologically dependent. The majority of doses are given by mouth. Figure 82-1 shows the maximum levels ever needed by all the patients among a group of 500 at the Hospice. The number needing more than a 30 mgm. dose at a time included a few who reached levels of 60 or even 90 mgm. Occasionally we need to be bold in the relief of pain and the fact that most patients do not need this should never lead to one of them failing to receive what for him is the only adequate dose. Even with these patients we may find then no further increase in dose for a period of weeks while relief remains good.

Dyspnoea, with its almost inevitable accompaniment of anxiety and nausea and vomiting, which are so often coupled with a most understandable depression, may demand more skill and confidence for their control than pain itself. Again, we may need to use heavy sedation with a small minority of patients, usually for a short time only.

Relief of Mental Distress

This includes all that we can learn of what it feels like to be so ill and of the stages of emotion which many seem to pass through.[1] We need to learn to recognize the difference between clinical depression (surprisingly rare in this situation) and sorrow or what has been called "the bereavement of the dying." Drugs may help the first but only the real listener will reach through to the second. We see anxiety and have to learn not to pass by. Patients, too, often come in with some such remarks as "It seemed so strange, no one wanted to look at me." Those who have come to terms with what is happening have so much to teach us if we will only come close enough to learn.

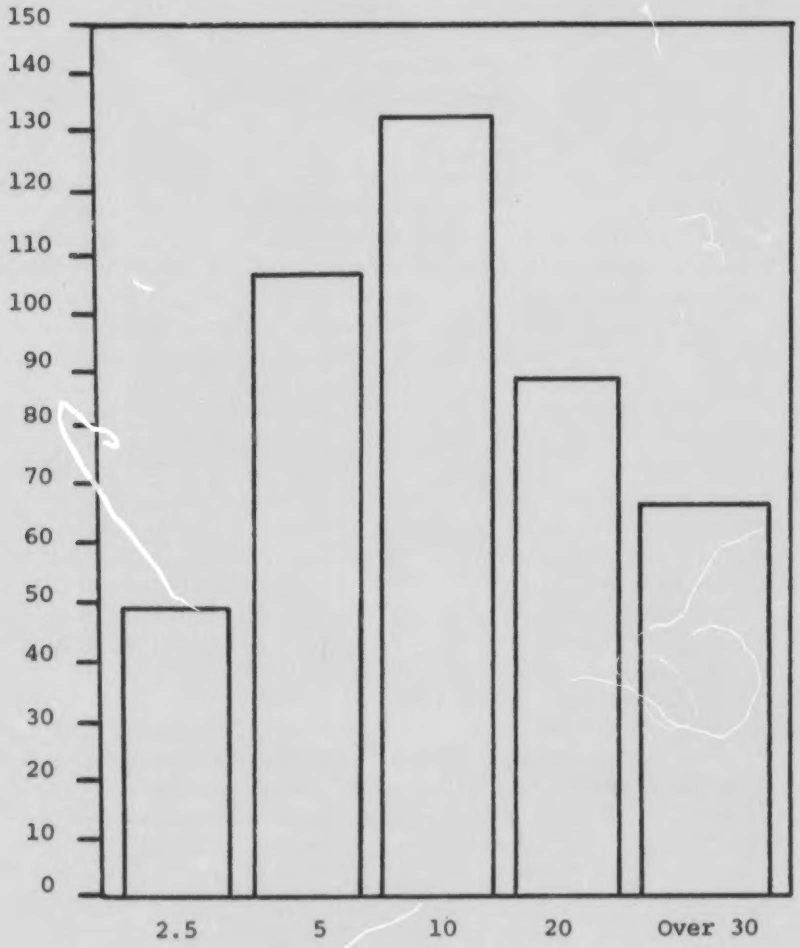

Figure 82-1

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The very old suffer deeply from weariness and the feeling that their years are a burden to others as well as to themselves. Confusion is sometimes a retreat from reality and whereas drugs may help here it is again the the listener who will reach through more positively. But just as isolation is a "state inaccessible to drugs"[2] so words may not reach and some needs can only be met by touch and silent communication.

## Care for the Spirit

There are many different ways in which people illustrate their fear of the future--the kind of dread which may be expressed as "I cannot die in meaninglessness." Spiritual care includes the personal and the informal but more often than might be expected people are helped by long-forgotten sacraments. This is not the province of the Chaplain only, any member of staff may be called on to remain, often without words, with a family or a lonely patient. Spiritual care includes all that we can do to bring a sense of security into the situation. Our own philosophy must never be imposed upon another person but an unspoken conviction that there is still purpose and meaning in his life may create a climate in which he can find his own answer.

How do the staff of such units involve themselves so deeply in the needs of the patients and still carry on? We have found that we need to meet constantly in small groups for discussion so that we share the work fully. A social psychiatrist visits weekly and sees about 15% of the patients but spends much of his time in such groups. The volunteers and visiting students, part-time staff, the elderly residents in their own Wing, and the children of the staff in their Playgroup, form a mixed community which gives mutual support.

## Decisions

Terminal care including the making of decisions concerning the correct treatment for an individual patient. There is a time for giving dexamethazone to a patient with a cerebral tumour but there is also a time to withdraw it. We have to concern ourselves with the quality of life as well as with its length and with the pressures imposed upon a family when we are maintaining what has become only a travesty of life. There are patients for whom chemotherapy gives great benefits but there are others for whom it becomes increasingly irrelevant, producing more side effects with diminishing returns. We must learn when to withdraw such treatment.

There are other manoeuvers (sic) which should never be undertaken. There are times when the treatment for a haemorrhage (sic) is not a blood transfusion with its attendant alarms but instead an injection and someone who stays there. There are infusions which should never have been put up, feelings of thirst can be relieved by the right use of narcotics. It is far better to have a cup of tea given slowly on your last afternoon than to have drips and tubes in all directions. This is not ineffectual sentimentality but proper care with all the compassionate matter-of-factness that the nuns of St. Joseph's Hospice and many other experienced nurses have shown us over the years. Again, we sometimes need to make decisions concerning the use of antibiotics and other measures for the very old or the very ill who develop pneumonia. There are ways of relieving the dyspnoea, cough and any other distress which do not prolong further a life which has come close. There are not "untreated" patients but rather those who have received the treatment relevant to their condition and so often to their wishes.

All the above would, we believe, be included in the "good medical care" as referred to by the President of this College in his opening speech. This kind of terminal care, which needs to be developed and shared between the general and the special hospital, the patient's own home and units of various kinds, is the answer to most of the fears which lead to support for the principle of voluntary euthanasia.

Requests?

A very small number of patients have wanted to discuss euthanasia with us. No one has come back to make a considered request for us to carry it out. Once pain and the feeling of isolation had been relieved they never asked again.

We had such discussions with two young men, both with motor neurone disease. One said, "If it were available I would ask." Yet he always demanded antibiotics if he had an incipient chest infection and he well knew how inconsistent were his feelings and wishes. Finally he said, "Yes I would have asked, but now I see the snags." Weighed against all his problems were his deepening relationship with his wife and his growing confidence that we would never let him choke. He died quietly in his sleep after a massive pulmonary embolus. The two of them had shared the hardness throughout and there were no guilts or hang-ups as his wife began her new life.

The other man died later. He found that the stage of physical helplessness in the first, which he had watched with apprehension, was totally different when he reached it himself. He maintained his essential independence, never giving in to anything and fought his way into a peace in which he could say, "I can't see round the next bend but I know it will be alright."

A young man said to me, as he faced leaving life and his strong family ties and responsibilities, "I've fought and I've fought--but now I've accepted." We, too, have to learn to accept as well as to fight and to realize that part of our work can have nothing to do with cure but only with the giving of relief and comfort. We will learn by looking at patients, by listening to what they want to say and by meeting their needs as far as we can both practically and philosophically. His readiness finally to say "yes" to death was in itself an affirmation of life. We need him as much and more than he needs us. Anything which says to the very ill or the very old that there is no longer anything that matters in life would be a deep impoverishment to the whole of society.

1. Kubler-Ross, Elisabeth (1970). On Death and Dying. Tavistock Publications, London.

2. Hackett, T.P., Weissmann, A.D. (1962), The Treatment of the Dying. Curr. Psychiat. Ther. 2:121

Reprint with permission: Saunders, CMS "The Care of the Dying Patient and His Family," Reister, S.J.; Dyck, A.J. and Curran, W.J. (eds.) Ethics in Medicine: Historical Perspectives and Contemporary Concerns, Cambridge, Mass Contact, Supplement 28, Summer 1972, pp. 12-18.

# VOLUME II: FACILITATOR MANUAL

## INTRODUCTION: COURSE OVERVIEW

### PURPOSE

During the past decade, the hospice has emerged as a significant and innovative model for the care of the dying patients and their families. The rapid proliferation of hospice care programs throughout the United States indicates the growing concensus on the need for more effective and humane care of the dying. The nurse holds a critical role in the coordination and provision of hospice care services. In this role, the nurse is frequently called upon to provide services that transcend the knowledge and skills obtained in existing nursing education programs.

The purpose of the Hospice Education Program for Nurses is to prepare nurses to work in hospice care programs. The curriculum is designed to develop the necessary knowledge and skills to enhance the nurse's ability to provide high quality care to dying patients and their families.

### INTENDED AUDIENCE

The Hospice Education Program for Nurses has been designed for nurses who are preparing to work, or are currently working, in hospice care programs. The curriculum has been designed for appropriateness for Associate Degree, Diploma and Baccalaureate prepared nurses who are currently registered.

It is recommended that an application form be utilized for the program to generate information for the instructors on the prior hospice related training experience of participants, prior work of participants in hospice programs, the current roles and positions held by participants, etc. This data can provide the instructors with some beginning assumptions about the level of sophistication of the participant group.

It is also recommended that the application form identify any participants who have experienced a death in their immediate family or intimate social network during the past year. This will indicate to the instructors persons who may require some additional emotional support during the course, and in particular during some of the structured learning experiences.

Participants need to know that persons going through the Hospice Education Program for Nurses often experience very strong emotions as they explore their attitudes, beliefs and values about death and inevitably explore their own personal experiences with the death of loved ones. The course announcement can include a statement that the course includes exercises designed to assist the nurse in exploring attitudes, values, beliefs and experiences with death and how these effect the caregiving process.

### COURSE GOALS

Upon completion of the Hospice Education Program for Nurses, each participant will:

- Understand the history and philosophy of hospice care and the different models of hospice care currently being provided in the United States
- Acquire communication and counseling skills which enable them to have effective and supportive interactions with dying patients and their families
- Develop a broad understanding of death, dying and grief
- Acquire an understanding of family dynamics and family centered approaches to the care of hospice patients and their families
- Develop personal and organizational strategies for managing professional stress experienced in the hospice care setting
- Increase their understanding of the physiological mechanisms and signs and symptoms of dying
- Acquire knowledge and skills of pain and symptom management in the dying patient
- Develop a framework for interdisciplinary team concepts which will enhance their understanding of and participation in the hospice health care team
- Explore the legal and ethical issues involved in caring for the dying patients and their families

## INSTRUCTIONAL METHODOLOGY

The instructional methodology combines didactic instruction and experiential learning. Various methods are used to make the learning process most effective: lecture, mediated demonstrations, simulations, task group exercises, guided group discussions, movies, field trips and individual reading assignments. Learning activities are designed to facilitate large-group and small-group interactions and to provide participants with an opportunity to practice skills they can use on the job. Each module provides adequate time for new information to be presented, analyzed and applied in practice sessions. There is an implicit expectation for active participation of all participants.

This manual provides a detailed outline of each of the nine course modules. Each module author has prepared a step-by-step description of the methods to be utilized in the presentation of his/her module. These instructions include a sequential outline of lecture material, discussion points, large and small group exercises, audiovisual presentations, etc.

## COURSE SCHEDULE

The Hospice Education Program for Nurses has been designed to facilitate a number of different delivery formats. Three of the basic delivery options are outlined in detail below.

### Delivery Option A: Two Week Concentrated Course

The course has been designed for a total instructional delivery time of 80 hours. The first option for delivering the course is to present the course in a concentrated two week time span. As such the delivery schedule would approximate the schedule on the following page. It can be seen from this schedule that there are 72 hours of structured activity with a total of 8 hours designated open time. Open time is merely unscheduled flexible time to be used at the discretion of the instructors to expand modules beyond their designated time to meet the particular needs of the participants.

The schedule also indicates two activities that are not covered in the later module descriptions: the clergy panel and the funeral home visit.

The instructors should organize a clergy panel presentation including representatives of major Protestant denominations, Roman Catholic, Jewish faiths and of any other major religious faiths in the geographical region. The purpose of the clergy panel is to:

- Present an interdenominational perspective of attitudes and beliefs toward dying
- Discuss various religious practices surrounding the death event and care of the body following death
- Delineate mourning, wake and funeral practices for various religions

The instructors should also organize a visit to a local funeral home. The funeral home visit should include:

- A review of the law regarding disposition and moving of the body including role of Coroner/Medical Examiner
- An explanation of steps the family goes through in negotiating funeral arrangements
- Viewing of caskets
- A review of costs - caskets, services, grave sites, etc.
- An explanation (and viewing, if possible) of the embalming process
- Any special information applicable to the burial process in the geographical region

## DELIVERY OPTION A: TWO WEEK CONCENTRATED COURSE

WEEK ONE

| | MONDAY | TUESDAY | WEDNESDAY | THURSDAY | FRIDAY |
|---|---|---|---|---|---|
| 8:00 | Introduction Course Overview | Module II | | Module III (Continued) | |
| 9:00 | Module I: Hospice Care Concepts | Communication Skills | Module III<br>Concepts of Death, Dying and Grief | | Module IV<br>Family Dynamics and Family Counseling |
| 10:00 | | | | Module IV<br>Family Dynamics and Family Counseling | |
| 11:00 | | | | | |
| 12:00 | | | | | |
| 1:00 | LUNCH | LUNCH | LUNCH | LUNCH | LUNCH |
| 2:00 | Module II | Module II | | | Clergy Panel |
| 3:00 | Communication Skills | Communication Skills | Module III (Continued) | Module IV Family Dynamics and Family Counseling | Open Time |
| 4:00 | | | | | |
| 5:00 | | | | | |

DELIVERY OPTION A: TWO WEEK CONCENTRATED COURSE (cont.)

WEEK TWO

| | MONDAY | TUESDAY | WEDNESDAY | THURSDAY | FRIDAY |
|---|---|---|---|---|---|
| 8:00 | | | Module VIIA Pharmacology | Module VIIB Pain and Symptom Management | Module IX Ethical and Legal Issues |
| 9:00 | Module V Managing Personal and Organizational Stress in the Care of the Dying | Module VI Understanding the Process of Dying and the Death Event | | | |
| 10:00 | | | | Module VIII Interdisciplinary Team Concepts | |
| 11:00 | | | | | Final Eval. & Closing |
| 12:00 | | | | | |
| 1:00 | LUNCH | LUNCH | LUNCH | LUNCH | LUNCH |
| 2:00 | | Module VI Understanding the Process of Dying and the Death Event | Module VIIB Pain & Symptom Management | Module VIII Interdisciplinary Team Concepts | Open Time |
| 3:00 | | Funeral Home Visit | | Open Time | |
| 4:00 | | | | | |
| 5:00 | | | | | |

Both the clergy and the funeral home director need to be scheduled with sufficient advance time to assure their adequate preparation for the presentations.

The following are a number of tips and suggestions for the successful delivery of the two week concentrated course.

1. Provide all participants with course manuals and reading assignments at least two weeks prior to the beginning of the course. This procedure is to reduce the amount of reading required during the course and thus minimize the exhaustion of participants.

2. Inform all participants that the course requires a full time two week commitment. Participants will be expected to be on time, participate for full days, attend all ten days of the course, and be called from the course only in cases of emergencies.

3. There are some advantages to conducting the training in a residential retreat format. This design increases the cohesiveness of the group , provides greater levels of emotional support to participants, and allows evening time to be used for reading and informal discussions. Participants who have to assume full spouse, parental and/or work responsibilities during the course and may find themselves physically and emotionally exhausted by the end of the second week.

4. The two week concentrated course requires careful attention to logistical details. These details (including course recruitment, distribution of course materials, arranging for facilities and equipment, ordering movies, arranging for the clergy panel and funeral home visit, etc.) can best be attended to by designating one person responsible for the overall organization and coordination of the course delivery.

5. Participants in the concentrated course should function as a closed group. Persons should not be allowed to drop in or attend individual modules who are not committed to participation in the full course. Allowing sporadic participation breaks up the cohesiveness and natural supports in the group and inevitably proves disruptive to the presentation of course material.

6. Given the length and subject matter of the course, the physical facilities where the course is hosted are particularly important. The physical space should be roomy, bright and well ventilated, filled with comfortable tables and chairs. The space should reflect that the course is designed for adult learners. The overcrowded, overheated classroom setting filled with desks/chairs designed for adolescent bodies is not appropriate for the delivery of this course.

7. It is particulary important in delivering the two week concentrated course to stay attuned to the potential for physical and emotional exhaustion of participants. Tailor the frequency and length of breaks, the balance between didactic and experiential learning, the extent

of reading assignments, etc. to the energy level of the group.

8. Instructors should be sensitive to participants who may need some extra emotional support during the course. Making the time of instructors available during breaks and other periods of free time is one way of structuring in such emotional support.

## Delivery Option B: Self Contained Workshops

The second method of delivering the course material is through a series of free standing workshops. The course has been designed so that each of the nine modules can be delivered independently as a workshop or seminar.

This option may be particularly appropriate where a target group of nurses has already received substantial training in some content areas of the course. In this case, those modules that are a high priority need can be offered in a workshop format without participants needing to complete the entire curriculum. In the workshop model, the sponsor would organize a presentation of one or more of the modules, recruit participants and host the workshop. The instructional guides in this manual provide the potential sponsor with a detailed listing of instructor qualifications, delivery time, space needs and equipment needs for each of the nine modules. When delivering the course material in this manner, the sponsor can reproduce and distribute the module of the Participant Manual that is the workshop topic without having to use the entire manual.

The workshops would be organized into one half day, full day, or one and a half day time blocks. This format would be adaptable and appropriate for continuing education, inservice and staff development programs.

## Delivery Option C: Integration into Nursing Curriculum or Continuing Education Programs

Each module of the Hospice Education Program for Nurses is divided into submodules that allows each module to be broken into relatively small time units. This design was intended to facilitate the integration of the curriculum into academic nursing education programs and continuing education programs. The curriculum could be taught as a complete course or material in various modules could be integrated into existing undergraduate and graduate courses. An example of how the material in the hospice modules could be integrated into traditional nursing school courses is illustrated on the following page.

|  | Hospice Module | Undergraduate Course | Graduate Course |
|---|---|---|---|
| 1. | Hospice Care Concept | Philosophy of Nursing<br>Medical Surgical Nursing | Oncology Nursing |
| 2. | Communication Skills | Foundations of Nursing | Nursing Management |
| 3. | Concepts of Death, Dying, and Grief | Psychiatric Nursing | Psychiatric Nursing<br>Pediatrics |
| 4. | Family Dynamics and Family Counseling | Community Nursing | Psychiatric Nursing<br>Community Nursing<br>Pediatrics |
| 5. | Managing Personal and Organizational Stress in the Care of the Dying | Professional Roles & Responsibilities | Nursing Management |
| 6. | Understanding the Process of Dying and the Death Event | Pathophysiology | Physiology |
| 7. | Pain and Symptom Management | Medical Surgical Nursing<br>Foundations of Nursing | Oncology Nursing<br>Medical Surgical Nursing |
| 8. | Interdisciplinary Team Concepts | Nursing Leadership | Nursing Management |
| 9. | Ethical and Legal Issues | Fundamentals of Nursing | Bioethics |

The division of the modules into submodules allows the course material to be easily presented in either one hour, one and one-half hour or three hour units.

The entire curriculum is equivalent to six credit hours or eight Continuing Education Units (80 contact hours).

## INSTRUCTIONAL MATERIALS

### Participant Manual

The Participant Manual contains the basic content of the course and the worksheets that participants will need for the large and small group exercises. Instructors should urge participants to read each module before its presentation and to use it during classtime for reference and to take notes.

### Facilitator Manual

The Facilitator Manual provides a basic outline of time and activities for use during each module.

It should be noted that the module on pain and symptom management is significantly different than all the other modules in that the bulk of the module content is in the Facilitator's Manual instead of the Participant's Manual. This particular module must be tailored to the specific learning needs of each particular participant group and, as such, requires more design work and adaptation than any other module.

### Flip Charts

Flip charts (or overhead transparencies) help organize and clarify information. They provide participants with a visual outline of the course content; information that is both seen and heard is more easily retained. Some hints for the effective use of flip charts:

- Prepare them in advance when you are presenting a lecture
- Use them to record points made (by participants) during a discussion or brainstorming session
- Use them to reinforce or clarify a teaching point
- Make sure the charts are visible to all participants
- Write legibly
- Be creative: Use colors and print variations if time and resources allow; leave areas to be completed by participant input, etc.

The following modules generally require two instructors when there are more than 15 participants in the course:

Module II: Communication Skills
Module IV: Family Dynamics and Family Counseling
Module V: Managing Personal and Organizational Stress in the Care of the Dying
Module VII B: Pain and Symptom Management
Module VIII: Interdisciplinary Team

The qualifications needed by instructors varies from module to module and are detailed for each module later in this manual. Where two instructors are utilized to deliver a module, it is recommended that at least one of the instructors have expertise in facilitating and directing small group learning exercises.

SPACE NEEDS

The delivery of the course generally requires one large meeting room that can comfortably accomodate up to 30 participants and enough area or additional rooms to accomodate up to seven small group discussions of five to seven participants. The space needs for each module are illustrated below:

| | MODULE | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Space Needs | I | II | III | IV | V | VI | VII | VIII | IX |
| 1 large Meeting Room to accomodate up to 30 persons | X | X | X | X | X | X | X | X | X |
| Area or rooms for 1 small group discussions of 5-7 participants each | | X | X | X | X | X | | X | |

EQUIPMENT NEEDS

The material and equipment needs for each module are illustrated below.

MATERIAL AND EQUIPMENT NEEDS

| MODULE | Name tags | Participant Manual | Instructor Manual | Prepared flip charts (or overhead transparencies | Flip chart easel | Blank newsprint pads | Markers | Masking tape | 35 millimeter movie projector | Movie screen | Slide projector | Pre-tests | Post-tests | Participant evaluation of training forms |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| I | X | X | X | X | X |  | X |  |  |  | X | X |  |  |
| II | X | X | X | X | X | X | X |  | X | X |  |  |  |  |
| III |  | X | X | X | X |  | X |  |  |  |  |  |  |  |
| IV |  | X | X | X | X | X | X |  | X | X |  |  |  |  |
| V |  | X | X | X | X | X | X |  |  |  |  |  |  |  |
| VI |  | X | X | X | X |  | X |  |  |  |  |  |  |  |
| VII |  | X | X | X | X |  | X |  |  |  |  |  |  |  |
| VIII |  | X | X | X | X |  | X |  |  |  |  |  |  |  |
| IX |  | X | X | X | X |  | X |  |  |  |  |  | X | X |

## INSTRUCTOR ROLES

The instructors for the Hospice Education Program for Nurses must perform a number of roles to assure the successful delivery of the course. Instructors must provide content expertise, serve as group facilitators, provide sensitive time and task management, and shape and maintain the overall learning climate.

### Provide Content Expertise

Each instructor should be aware of the overall course design and content and thoroughly familiar with the content of the module(s) which they are responsible for delivering. Each instructor is expected to integrate their own knowledge and experience into the delivery of course material. The course design requires that instructors present the module content, answer participant questions, and, in some modules, demonstrate the skills being studied. Instructors are also expected to serve as technical advisors to individuals and small groups during the structural learning exercises.

### Act as Group Facilitator

Instructors must play a key role in monitoring the process of work groups. During exercises, the instructors should float between groups to provide any clarification of instructions or needed facilitation of the small groups. If staff from a number of programs are represented, try to structure exercises and breakdown of groups so that cliques and subgroups don't form by program affiliation.

A note of caution is warranted here. There are both personal and local program issues that can arise during the instruction and group exercises. Many of these issues cannot be effectively addressed or resolved within the framework of the course. Instructors should help set these issues aside or contract to work on them outside the time allotted for the course. It is crucial that ideological differences, inter- and intraprogram difficulties, etc. not become a central issue in the course. The focus on knowledge and skill acquisition can be maintained by the instructor keeping control over the specific tasks in each section of each module.

### Provide Time and Task Management

The volume of the material and the number of learning experiences built into this course requires that the instructors maintain very clear time boundaries and remain highly task-oriented. While instructors are free to lengthen or shorten modules based on the needs of the participant group, it is critically important to manage time so that all the modules can be adequately covered within the overall time constraints of the course.

### Maintain the Learning Climate

This course combines a large body of didactic information with highly task-oriented structured learning experiences. It is important for the instructor to recognize that this combination can become fatiguing, particularly given the emotional responses often evoked from the subject matter. The instructors must structure breaks, group energizers, alternative exercises, etc. based on the energy level of the group.

## PREPARING TO DELIVER THE COURSE

Implicit in the use of this course is a willingness to work with materials developed by others. This in turn requires a willingness to spend adequate time in mastering the course material and delivery methodology and making needed refinements for the particular participant group. Instructors should be prepared to elaborate on course content and to provide additional examples and exercises needed to make the material as applicable as possible to participants. Additional background reading for each content area is contained in the bibliography that accompanies each module.

The overall preparation for the delivery of this course should include the following:

- Instructors should review the participant recruitment forms to ascertain the educational and experiential backgrounds of participants

- Where a module is to be team taught, the instructors should meet together to finalize the module schedule and to assign responsibility for each lecture, exercise, demonstration, etc.

- The instructors should study this manual and the Participant Manual and then make any needed modifications in the module based on the needs of participants

- All instructional materials, i.e. overhead transparencies or flip-charts must be prepared in advance

- Reproduction of pre-tests, post-tests, and other evaluation instruments (see Appendix) must be prepared in advance

## PRACTICUM EXPERIENCE

It is recommended that a clinical practicum accompany the classroom instruction. The design for the practicum experience will vary greatly from area to area based on the availability of hospice care programs. Appendix A of this manual outlines alternative designs and guidelines for the organization of the practicum experience.

## EVALUATION

The Hospice Education Program for Nurses has been designed to include up to five evaluation elements:

1. Each participant will take a pre-test at the beginning of the course and a post-test at the conclusion of the course. These tests measure learning gains that have been acheived during the instruction

2. Participants will receive formal and informal feedback on skill mastery from the instructors during the learning exercises dispensed throughout the nine modules.

3. Each participant that participates in a clinical practicum will receive a narrative evaluation report from the practicum supervisor.

4. Each participant will be asked to complete an evaluation of each of the nine modules. This evaluation instrument provides you with an opportunity to assess the clarity, completeness, organization, utility and presentation of each module.

5. Each participant will be asked to complete an evaluation of the complete Hospice Education Program for Nurses. This evaluation instrument provides you with an opportunity to comparatively assess the modules and the presentors, rate the organization of the overall program, rate the instructional materials, and rate the instructional facilities.

Appendix B of this manual contains the description of the evaluation procedures and samples of the evaluation instruments.

# MODULE I: HOSPICE CARE CONCEPTS

## FACILITATOR MANUAL

BY

Florence Wald, R.N., M.S.

# MODULE I: HOSPICE CARE CONCEPTS

## Purpose and Goals

The purpose of Module I is to introduce the concept and philosophy of hospice to the participant. The goals of the module are to assist the nurse in:

- Identifying why hospice care is needed for dying patients and their families
- Understanding the rights of patients and families
- Recognizing the multidisciplinary approach of hospice care
- Developing a sensitivity to the physical, psychosocial and spiritual needs of dying patients and their families

## Module Content

The module content includes the following areas:

- Historical review of medical/nursing care in institutions in the United States
- Development of hospices in the 20th century
- Rationale for palliative care
- Assumptions and principles underlying standards for terminal care

## Learning Objectives

At the conclusion of Module I participants will be able to:

- Describe why reform of care for dying patients and their families was needed
- Identify the dehumanization of patients which was occurring in traditional institutions before reforms were instituted
- Name two individuals responsible for reform of care of terminally ill patients
- List five forms of hospices which have evolved
- Discuss The Assumptions and Principles of Terminal Care
- Discuss the rights of patients and their families in involvement of care

- State the assumptions and principles underlying standards for terminal care
- Define hospice
- Describe the hospice philosophy of care of the terminally ill

## Perspective

The material presented in this first module sets the tone for the rest of the course. Participants should develop an awareness and understanding of the historical bases of care of the ill, and specifically the dehumanization of the terminally ill, in our highly technologized society with its complex system of care. The module has been designed to stimulate thought in the participant regarding his/her philosophy of care of the terminally ill and to surface feelings regarding quality of life. It is anticipated that discussion will ensue around the issue of why other health care settings and delivery systems are unable to meet the needs of the dying patient and his family. It is expected that the facilitator will present his/her own philosophy and history of their particular hospice unit during the slide presentation. The slide presentation should reflect philosophy of care of the particular institution and should show physical facilities and patients who are receiving care. It should be noted that the National Hospice Organization Standards have been purposely omitted from this module at this time as they are currently under review. It is expected that the facilitator will obtain the current standards from the National Hospice Organization and present them in this module.

Module I has been designed for a total of three hours of instructional time. The approximate breakdown is as follows:

| | |
|---|---|
| Didactic presentation of module content | 2 hours |
| Film: How Could I Not Be Among You | 1 hour |

## Staff Requirements

One instructor is required for presentation of this module. The optimum group size is 20 with a maximum effective number of 30. For credibility the instructor should:

- Have extensive knowledge of care of the terminally ill and clinical experience in a hospice setting

## Space Requirements

Space requirements for Module I include one large meeting room.

**Material Needs**

The equipment and materials needed for Module I include the following:

- Facilitator manual for instructor
- Participant manual for each participant
- Name tags
- 35 millimeter slide projector
- Movie screen
- 16 millimeter movie projector
- Newsprint tablet
- Magic markers

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | REGISTRATION |
| | The instructor should arrive early to greet participants as they arrive and to check for any last minute adjustments of the physical space (e.g., room temperature, arrangements of chairs, etc.). Audio visual equipment should be set-up during this time. |
| | WELCOME AND ADMINISTRATIVE DETAILS |
| | Purpose |
| | ● To quickly complete administrative tasks needed to facilitate the delivery of the module |
| | Instructions |
| 5 minutes | Following introduction of instructor and introductory remarks, cover the following: |
| | ● Expectation for active participation |
| | ● Break times |
| | ● Restroom locations |
| | ● Location of refreshments during breaks |
| | ● Eating places |
| | ● Climate setting |
| | - Define setting (large meeting room) |
| 10 minutes | Instructor should introduce course and Module I. Review: |
| | ● Objectives |
| | ● Purpose |
| | ● Content |
| | Hand out pre-test and skills inventory |
| 45 minutes | Administer pre-test |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Instructions: |
| | Instruct participants to circle correct answer on multiple choice pre-test. |
| | Administer skills inventory. |
| | Instruct participants to complete skills inventory sheet. |
| | I. Hospice Care Concepts |
| 15 minutes | Purpose |
| | • To introduce concepts regarding care of the terminally ill |
| | • To describe the hospice philosophy of care |
| | Note: |
| | The instructor should integrate his/her hospice experience, give case examples and present specifics of his/her particular hospice throughout this module. |
| | Slide Presentation |
| | Purpose |
| 35 millimeter slide projector | • Present an overview of the instructor's particular hospice |
| Screen | The instructor should prepare a slide presentation which will provide an overview of his/her hospice for participants. During this presentation the instructor should present: |
| | • The hospice's philosophy of care |
| | • The hospice's setting |
| | • The physical layout |
| | • Types of patients |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • Members of the interdisciplinary team<br>• The hospice's facilities<br>The instructor should draw upon his/her personal experiences during this presentation. The type of care methods of implementation of care and types of patients to whom care is given and should be delineated. The instructor should integrate case examples throughout the presentation. If at all possible pictures of actual hospice patients should be presented. The major point of the slide presentation is to bring the learning experience from a general discussion of hospice care to a specific presentation about a given hospice program.<br>This slide presentation should be integrated throughout the module.<br>It is expected that the instructor review the attached articles prior to developing lecturettes for this module and that material contained in the articles will be incorporated into the lecturettes.<br>II. Reform of Care During a Terminal Illness<br>Purpose |
| 15 minutes | • To identify why reform of care during a terminal illness was needed<br>Instructions<br>Develop a lecturette based on pages 3-5 of the participant manual<br>Present the lecturette stopping periodically to allow participant's discussion. The following content should be addressed:<br>- Depersonalization of care<br>- Technologized medical/nursing care<br>- Pathology rather than person-focus<br>- Quality of life<br>- Economic cost<br>- Conflicting demands of teaching, research and intensive care |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | - Changing nursing roles<br>- Feeling of powerlessness by nurses<br>- Lack of community resources<br>III. The Beginning of Reform<br>Purpose |
| 15 minutes | ● To identify the beginning of reform of care of the terminally ill<br>● To describe organizations which were founded to examine attitudes and obligations of individuals regarding care for the terminally ill<br>Instructions<br>Develop a lecturette based on pages 6-10 of the participant manual<br>Present the lecturette highlighting the following:<br>- The historical bases for change<br>- The work of Ida Orlando<br>- The Society for Health and Human Values<br>- Journals specific to death and dying<br>- The work of Drs. Cicely Saunders and Elizabeth Kübler-Ross and their impact on the delivery of care to the terminally ill<br>Allow time for questions from participants |
| 15 minutes | BREAK<br>IV. Cure and Palliative Care<br>Purpose<br>● To delineate differences between curative and palliative care<br>Instructions<br>Develop a lecturette based on pages 10-14 of the participant manual |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Present the lecturette in didactic form |
| | The following should be included: |
| | - Description and definition of the Assumptions and Principles of Terminal Care |
| | - The interchange between the two systems of cure and palliation |
| | - The Krakoff model |
| Newsprint Tablet<br>Magic Markers | - Describe the five forms of hospices which have evolved. List on newsprint |
| | - Present a case example of a dying patient and his/her needs, and the needs of the family, identifying how these needs can best be met in a hospice |
| | - The instructor shall list on newsprint, and discuss the names and types of hospices found in his/her particular geographic area |
| | V. Assumptions and principles underlying standards for terminal care |
| 15 minutes | Purpose |
| | ● To describe the three groups of Assumptions and Principles |
| | ● To discuss the Principles and their underlying Assumptions |
| | Instructions |
| Newsprint tablet<br>Magic Markers | The instructor should like and number the Principle on the left side of the newsprint in one color ink, with the Assumptions listed on the right side in another color ink |
| | A lecturette should be developed based on pages 15-19 of the participant manual |
| | Present the lecturette referring to the list of Principles and Assumptions on the newsprint tablets |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Note:<br>Five minutes are allotted for each of the Principles and Assumptions. The instructor should allow for input from participants. Fifteen minutes are allotted to each of the following:<br>• Patient-Oriented Principles and Assumptions<br>• Family-Oriented Principles and Assumptions<br>• Staff-Oriented Principles and Assumptions<br>Examples should be given by the instructor, from his/her hospice experience, which will utilize and/or apply concepts within the Principles and Assumptions. |
| 5 minutes | VI. National Hospice Organization Standards |
| 5 minutes | Purpose<br>• Review current standards<br>Instructions<br>The instructor should obtain the current standards of the National Hospice Organization. These may be obtained by contacting the National Hospice Organization, Vienna, Virginia. The current standards should be reviewed with participants |
| 40 minutes<br>16 millimeter movie projector<br>Screen<br><br>Newprint<br>Magic Markers<br>15 minutes | VII. Film: How Could I Not Be Among You<br>Instructions<br>Show the film "How Could I Not Be Among You" available from most public libraries. Instruct the participants to identify beliefs and attitudes toward death and dying. Following the film solicit observations of the participants and list their observations on newsprint<br>Note:<br>The instructor may also utilize this time to solicit feelings, attitudes and beliefs of participants, in a non-threatening environment, regarding care of the terminally ill and the hospice philosophy of care. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | VIII. Summary |
| 10 minutes | Instructions |
|  | Close the session by summarizing the major points discussed throughout the session |
|  | Answer any questions which participants may have |
|  | Adjourn |

# MODULE II: COMMUNICATION SKILLS

## FACILITATOR MANUAL

DEVELOPED BY:

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# MODULE II: COMMUNICATION SKILLS

## PURPOSE AND GOALS

The purpose of Module II is to develop and/or refine the skills of the hospice care nurse in communicating with the hospice patient/family. The goals of the module are to assist the hospice nurse in responding to the psychosocial needs of the dying patient and family through:

- The mastery of basic communication (attending, listening, responding) behaviors
- The mastery of basic instructional methods to teach the family patient care procedures

## MODULE CONTENT

The module content includes the following areas:

- Assumptions and values
- Attending Behaviors
- Encouraging Verbal Communication
- Paraphrasing
- Reflection of feeling
- Summarizing
- Self Disclosure
- Confrontation
- Problem Solving
- Reassurance and Support
- Teaching functions in hospice
- Applying communication skills to teaching
- Methods of small group instruction
- Adult learning principles

- Design of learning experiences
- Teaching styles

## LEARNING OBJECTIVES

At the conclusion of Module II, participants will be able to:

A. Demonstrate the following seven basic communication skills reviewed in the module

  - Attending behaviors
  - Encouraging verbal communication
  - Paraphrasing
  - Reflection of feeling
  - Summarizing
  - Self disclosure
  - Support and Reassurance

B. Demonstrate knowledge and skills in hospice teaching by:

  - Identifying at least three teaching roles in hospice
  - Explaning at least two characteristics of teaching roles
  - Identifying the three basic stages of group development
  - Defining the terms 'content' and 'process'
  - Identifying the goals of teaching in each phase of group development
  - Self-identifying preferred teaching modes
  - Designing and delivering a 5-10 minute learning experience

## PERSPECTIVE

The nurse moving from traditional medical care settings to the hospice program must develop new perspectives and orientations to the nature of patient care and the nurse's role in this care. One of the most major changes in hospice care is the emphasis placed on meeting the psychosocial needs of the dying patient and their family. Meeting such needs requires a refinement and expansion of the nurse's communication skills.

We have placed the Communication Skills Module early in the curriculum because we see the skills in this module as the basic foundation upon which the remaining modules are built. The early placement of the module and the design of the exercises are also intended to help develop an atmosphere of trust and to enhance the cohesiveness of the participant group.

The module has been organized into two major sections. Section A is designed to provide an overview of basic communication skills. Ten components of the communication process are reviewed with accompanying experiential exercises intended to sharpen the nurses' expertise in each of the respective skill areas. Section A focuses primarily on the nature of the communication process between the nurse and the patient/family. Section B looks specifically at the nurse's teaching roles in the hospice program. In recognition of the major role nurses play in teaching family members patient care procedures in the home, we have designed Section B to sharpen the nurses' instructional skills with family members and other members of the interdisciplinary hospice team.

Module II has been designed for a total of 13 hours of instruction time. Section A on basic communication skills is designed for 8 hours of delivery time and Section B on teaching skills has been designed for 5 hours of delivery time.

## STAFF REQUIREMENTS

Two instructors are needed to present this module. The optimum group size is 20 with a maximum effective number of 30.

Given the nature of the material and the need to adapt the exercises to the skill level of various groups, instructors must ideally:

- Have at least one years experience training communication and counseling skills to health professionals
- Have a working knowledge of the nature of the nurse - patient/family relationship in hospice programs

- Have one or more years experience in group dynamics and task oriented instruction of health professionals
- Have experience in learning or curriculum design or in the training of instructors

## SPACE REQUIREMENTS

Space requirements for Module II include one large meeting room with sufficient space to spread out a maximum of 10 groups of 3 participants during the learning exercises. Section B will require an additional two rooms for small group meetings.

## MATERIAL NEEDS

The equipment and material needs for Module II include the following:

- Participant Manual for each participant
- Instructor's Manual for each instructor
- Prepared flip charts outlining module content (use of overhead projector and prepared transparencies can be substituted as per preference of the instructor)
- Four flip chart pads
- One flip chart easel
- Markers
- Masking tape
- 35 millimeter movie projector
- Movie screen
- Movie noted in Instructional Activity Sequence

## INSTRUCTIONAL ACTIVITY SEQUENCE

The instructional activity sequence is displayed on the following pages.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Note on Time Allocation and Modification of Exercies |
| | We anticipate that this module will need the most on site modification of all the nine modules of the curriculum. Each instructor must make a judgement as to the aggregate skill level of the participants and modify didactic presentations and experiential exercises to match this level. With groups that have not had training in communication skills or who need a complete refresher course, it is important to place heavy emphasis on the first four skill areas. With such a group, the instructor may want to expand the time allocation for such skill areas as attending, encouraging verbal communication, and paraphrasing. With groups who have had training in communication skills, greater emphasis should be placed on some of the skill areas that nurses have not frequently utilized within traditional medical settings, e.g., reflection of feelings, self-disclosure, confrontation, and problem solving. |
| | Instructors are also encouraged to modify exercises or substitute other types of learning exercises that will more adequately meet the skill needs of a particular participant group. |
| 1:00 - 1:15 | Introduction to Module II |
| 5 minutes | Introduce the module by reviewing the module goals, module content, and learning objectives. Note that the module is divided into two submodules: |
| Prepared flip charts | A. Basic Communication Skills |
| | B. Teaching Skills |
| | It is also important to note: |
| | • The importance of Module II to subsequent modules<br>• The importance of active participation in the learning exercises<br>• The importance of mutual support and feedback on skill mastery |

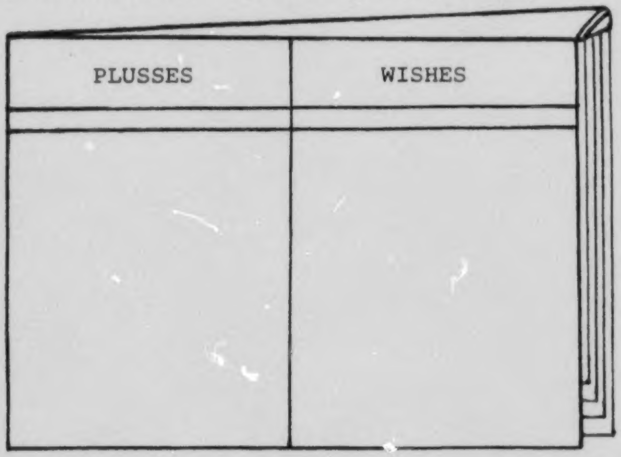
| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | SUBMODULE A: BASIC COMMUNICATION SKILLS |
| 1:15 - 1:45 | 1. Assumptions and Values |
| 10 minutes<br>Prepared flip charts | Present a 5 to 10 minute lecturette based on pages 4-5 of the Participant Manual. Discuss the dangers of unchecked assumptions through the following exercise. List the following on a flip chart: |
| 10 minutes | Behavior — Assumption — Alternate Assumptions<br>a. Patient crying in their room<br>b. Family does not visit patient in hospice<br>c. ____________<br>d. ____________<br>Ask participants to list assumptions one might make based on the behavior in #'s 1 & 2, and to then list alternative assumptions that could also explain the same behavior.<br>Ask participants to then list additional behaviors, assumptions, and alternate assumptions. Reviewing the list, identify what communication mistakes could be made by the nurse acting as if the assumptions were correct. |
|  | Note that many of the skills we will be focusing on in Module II are skills that help us check out assumptions we make about the needs of patients and families. |
| 10 minutes | Solicit situations from participants where value differences and conflicts between nurse and the patient/family might present major barriers to communication. List suggestions on flip chart. Suggestions could include such areas as strong religious differences, differences in beliefs about involvement of children in family mourning rituals, etc. Discuss with participants how such value conflicts can be addressed |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | personally and programmatically. |
| 1:45 - 2:15 | 2. Attending Behaviors |
| 10 minutes<br>Prepared flip charts | Present a 10 minute lecturette based on pages 6-9 of the Participant Manual. |
| 15 minutes | Explain to the participants that the two instructors will demonstrate an interview between a nurse and a patient's family member. The participants are to list all behaviors that demonstrate effective attending skills and all behaviors that indicate poor attending skills. |
| | Pick any situation and orient participants as to nature of interview, where it is to take place, etc. The two instructors should then role play the interaction for about 3-5 minutes with the attending skills of the nurse role exaggerated to their worst extreme. The role play should demonstrate poor listening behavior by exaggerating these behaviors to their grotesque extreme. The nurse role could, for example: |
| | ● Stare or show no eye contact<br>● Slouch and get up and move around the interview room<br>● Interrupt the family member<br>● Change topics constantly<br>● Chain smoke<br>● Sit too close or too far<br>● Etc. |
| 5 minutes | This role play loosens up the group and graphically dramatizes nonattending behavior. At the conclusion of the role play, those nonattending behaviors noted by the group should be listed on newsprint. |
| 2:15 - 2:30 | BREAK |
| | Attending Behaviors (continued) |
| 2:30 - 3:15<br>40 minutes | Inform the group that we will now carry out an exercise that will allow each participant to practice their attending skills. Instruct participants to self select into groups of three. The |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| Attending Feedback Form in Participant Manual | roles in the exercise are sender, receiver, and observer. The sender's role is to talk for five minutes about how they first became interested in the hospice movement. The receiver's role is to demonstrate effective attending behaviors to the sender. The observer's role is to time the interaction, to let the receiver and sender know when five minutes is up and to carefully observe the attending behaviors of the receiver using the Attending Feedback Form. |
|  | Following the 5 minute interaction, the observer reports to the receiver those behaviors observed during the interaction. Following this report out, both receiver and sender share how they felt in their respective roles. |
|  | The exercise is thus conducted in three phases: |
|  | a. Interaction - 5 minutes<br>b. Report of Observer - 5 minutes<br>c. Sharing by sender and receiver - 5 minutes |
|  | The participants then shift roles and repeat the exercise. The exercise is thus repeated three times so that each participant has an opportunity in each of the three roles. |
|  | The Instructors should float from triad to triad during these exercises to assist with any needed facilitation or clarification of directions. |
| 5 minutes | When all the triads have completed the exercise, bring participants back into the large meeting areas and review with the entire group how it felt to perform in each of the roles. |
| 3:15 - 3:50 | 3. Encouraging Verbal Communication |
| 10 minutes<br>Prepared flip charts | Present a 10 minute lecturette based on pages 12-14 of the Participant Manual. After reviewing the uses of open and closed questions and minimal leads, set up the following exercise. Instruct the group to break into dyads. Each pair will play either sender or receiver roles. During the first five minutes, the receiver is to interview |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 20 minutes | the sender to get more acquainted using only closed questions. During the second five minutes, the interview is to continue, using only open questions. The members of the dyads then switch roles and the exercise is repeated. |
| 5 minutes | Following the exercise, conduct a short large group discussion of:<br>A. How did it feel to be interviewed with only closed questions?<br>B. How did it feel to interview using only closed questions?<br>C. How did it feel to be interviewed with only open questions?<br>D. How did it feel to interview using only open questions? |
| 3:50 - 4:05 | 4. Paraphrasing |
| 5 minutes | Present a 5 minute lecturette based on pages 15-16 of the Participant Manual. |
| Prepared flip charts | Present the following on prepared flip charts and ask participants to write down an effective paraphrase response to the patient/family member statements. Allow a few minutes to complete each paraphrase and then solicit sample responses from the group. |
| 10 minutes | Patient: I haven't seen my brother Jim in 12 years.<br>Nurse: ______________________<br>Patient: I wanted to die at home but my family insisted I come to the hospital.<br>Nurse: ______________________<br>Patient: The Doctor never told me what was wrong until last week. If I'd only known, I would have done things differently.<br>Nurse: ______________________ |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Spouse: My husband is in constant pain and no one seems to be able to help him. |
|  | Nurse: ____________________ |
|  | Daughter: I couln't possibly care for my father at home; it's too much responsibility. |
|  | Nurse: ____________________ |
| 4:05 - 4:50 | 5. Reflection of Feeling |
| 10 minutes<br>Prepared flip charts | Present a 10 minute lecturette based on pages 17-18 of the Participant Manual. |
| 30 minutes<br>Reflecting Feeling Feedback Form in Participant Manual | Inform the group that we will now carry out an exercise that will allow each participant to practice their skills in reflection of feeling. Instruct participants to self select into groups of three. The roles in the exercise are sender, receiver and observer. The sender's role is to talk for five minutes on the feelings he/she experienced at the first death, or at the first wake/funeral attended. The death experience may be that of a patient, family member, friend or pet. The receiver role is to demonstrate effective reflection of feeling behavior to the sender. The observer's role is to time the interaction, to let the receiver and sender know when five minutes is up and to carefully observe the reflection of feeling behaviors of the receiver using the Reflection of Feeling Feedback Form. Rotate roles until all persons have performed in all three roles. |
| 5 minutes | When all the triads have completed the exercise, bring participants back together and review with the entire group how it felt to perform each of the roles. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 4:50 - 5:00 | CLOSING EXERCISE - LARGE GROUP<br>Take 5 minutes to summarize the day's activities and overview the skill area that will be covered the next day.<br>Close the day with the following exercise. Give the following instructions:<br>We want to close the workshop today by getting your feelings about what we've done today. We will utilize your input to make any needed changes in the workshop format for tomorrow morning. This exercise is called "Plusses and Wishes." (REFER TO FLIP CHART)<br> <br>We will begin by asking what the plusses were for today - those aspects of the learning you felt best about.<br>(WRITE THESE ON THE FLIP CHART UNDER THE PLUSSES COLUMN AS THEY ARE GIVEN BY PARTICIPANTS.)<br>Now what do you wish would have happened today that didn't?<br>(WRITE ITEMS ON THE FLIP CHART UNDER THE WISHES COLUMN AS THEY ARE GIVEN BY PARTICIPANTS.)<br>Wish everyone a pleasant evening and adjourn for the day. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 8:00 - 8:15 | 6. Summarizing |
| Prepared flip charts | Present a short 5-10 minute overview of summarizing based on pages 20-21 of the Participant Manual. Note that we will not be doing structured exercises on summarizing. Respond to only questions and issues that surface during the overview. |
| 8:15 - 9:15 | 7. Self-Disclosure |
| 10 minutes<br>Prepared flip charts | Present a 10 minute lecturette based on pages 22-23 of the Participant Manual. |
| 25 minutes | Ask participants to self-select into groups of 5-7. Each group is to select a recorder and discuss:<br>When and under what conditions is self disclosure an appropriate and helpful intervention with a dying patient or family member. When would self disclosure not be appropriate. The recorder should note on newsprint the major discussion points of the group. At the conclusion of the discussion, each group should select someone to present their major discussion points to the large group. |
| 25 minutes | Each group reporter should then take 3-5 minutes to report out the major points of discussion in their group. |
| 9:15 - 10:00 | 8. Confrontation |
| 10 minutes<br>Prepared flip charts | Present a 10 minute lecturette on confrontation based on pages 24-25 of the Participant Manual. |
| 10 minutes | The instructors should present a patient/nurse interaction around the issue of whether the patient wants to die at home or in the hospice. One instructor role plays the patient the other the nurse. The patient should communiate that he/she really wants to die at home but contradicts this point of view a number of times in the interaction and interjects various family members feelings/attitudes; the role of the nurse is that of attending. |
|  | After 5-10 minutes of the role play, the participants should be asked to identify the contradictions |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | List on flip chart pads and give suggestions for ways that the nurse could confront these contradictions. |
|  | The role play should dramatize contradictions and incongruities such as:<br>● The patient wants to die at home but thinks he might be less afraid in the hospice<br>● The patient is unsure about the family's willingness to have him at home, i.e., "I want to be at home but I'd be such a burden on my family."<br>● The patient says, "It really doesn't bother me that the family hasn't been to see me this week" but is teary-eyed, slumped posture, with flat affect. |
| 10 minutes | The trainors (then) resume role play incorporating the suggestions of the group. The patient can assume a passive or threatened role. The role play should continue for 5-10 minutes. |
| 15 minutes | Discussion following this second role play should focus on the confrontation. Questions which should be answered include:<br>a. How did the nurse confront the patient<br>b. Was the confrontation done in a positive or an attacking manner<br>c. How did the patient respond to the confrontation<br>d. What should the nurse do/say next |
| 10:00 - 10:15 | BREAK |
| 10:15 - 10:45 | 9. Problem Solving |
| 5 minutes<br>Prepared flip charts | Present a 5 minute lecturette based pages 26-27 of the Participant Manual.<br>The primary purpose of the exercises will be to teach participants how to do the force field analysis step of the problem-solving process. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 20 minutes<br>Force field worksheet from Participant Manual | Begin by presenting to the large group a typical problem-solving situation within a hospice program. The problem is that Mrs. C does not have transportation to get in to see her husband who is on an inpatient hospice unit. The desired direction of change is to arrange some form of transportation to get Mrs. C into see her husband daily.<br>Ask the group to think of similar situations they have encountered and generate a list of those forces working for a possible change in the situation. Examples might include:<br>• Spouse lives only a short distance from the hospice unit<br>• Spouse has numerous relatives and friends who could potentially share the transportation responsibilities<br>• Hospice program has extensive volunteer program that could help with transportation<br>• There are churches that have volunteered the services of their members to help transport needy families<br>• Etc.<br>Then have the group generate a list of those forces working against change of the situation. Examples might include:<br>• Family does not have a car<br>• Spouse cannot drive or use public transportation to to physical disability<br>• Spouse has difficulty asking family and friends for help for fear of imposing<br>• Family is indigent and cannot afford to pay for daily transportation services<br>As the group to generate alternative approaches based on the lists they generated. Emphasize to the group that strategies may seek to increase those forces inhibiting change. List the alternative on newsprint. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 20 minutes | Now ask each participant to write a problem statement on a piece of paper. The problem can relate to their personal or professional life. Inform them that they will not be asked to share the problem they have selected. Direct participants to then write a statement indicating the nature of the desired change they desire. Then ask each participant to complete the Force Field Worksheet on the particular problem they have selected.<br>Give participants 15-20 minutes to complete the worksheet and then ask them if the force field analysis helped clarify their perception of the problem or their view of potential approaches to the problem. |
| 10:45 - 11:00 | 10. Support and Reassurance |
| Prepared flip charts | Present a 10-15 lecturette and discussion based on pages 28-29 of the Participant Manual. |
| 11:00 - 12:00 | Closing Exercise |
| | The purpose of the closing exercise for Submodule A of Module II is to look at the various communication skills in an integrated manner.. |
| 30 minutes | Show the film "Mrs. Reynolds Needs A Nurse" available from Association Films - McGraw Hill Films (ordering information 714-453-5000) Belmar, California. |
| Movie projector screen | Instruct participants to identify the communication skills demonstrated in the film and to note other skill interventions that could have been used.<br>Following the film, solicit the observations of the participants and note the observations on newsprint.<br>During the last few minutes review the major skill areas that have been covered in the submodule. Conclude the submodule by noting that there will be opportunities throughout the learning experiences in the remaining modules to continue to practice the skills that were reviewed. |
| 12:00 | Adjourn the group for Lunch |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | SUBMODULE B: APPLYING COMMUNICATION SKILLS TO HOSPICE TEACHING FUNCTIONS BACKGROUND READING |
| 1:00 - 1:05<br>5 minutes | Open the session with a discussion and overview of the submodule explaining the goal:<br>To enhance participant's ability to understand, design and conduct learning experiences. The submodule content areas include: |
| Flip Chart of Content Areas | ● Understanding the teaching process<br>● Teaching functions in hospice<br>● Teaching skill areas in hospice<br>● Teaching in the small group setting<br>● Teaching style<br>● Learning environment and assumptions |
| | Note that the submodule will conclude with participants using a learning design tool, preparing and presenting a short learning experience for each other. |
| 1:05 - 1:20 | 1. Understanding the learning process |
| 10 minutes | Develop a lecture based upon the ideas and material presented on pages 1-3 of the background reading.<br>Note especially that:<br>● Most people have an image of teaching that involves the instructor in the role of authority<br>● Teaching in hospice must involve a more dynamic role for the nurse in a teaching situation<br>● Alienation of learners in hospice teaching cannot be tolerated the way it seems to be in other educational settings |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | ● The hospice teaching roles and function require substantial self-knowledge and good communication skills on the part of the hospice nurse |
| | Encourage the group to think about the best learning situations they have encountered. |
| | Ask the group to identify the best and worst learning experience they can recall. Ask them to describe:<br>● The environment<br>● Their own needs and expectations at the time<br>● The role and style of the person doing the instruction<br>● Any other factors that made the experience successful/unsuccessful |
| 5 minutes | Call upon members of the group to describe their recollections. |
| | Note: Factors creating a successful learning experience for one person may be the same as those creating an unsuccessful experience for another. The point here should be that success/failure in the learning situation is dependent upon many factors, including very individual preferences. |
| 1:20 - 1:30 | 2. Teaching functions in hospice |
| | Develop a lecture based upon the material and ideas presented on pages 3-5 of the background reading. |
| | Note especially that there are three principal learning audiences with which the hospice nurse is concerned:<br>● The patient/family<br>● The interdisciplinary team/staff<br>● The community |
| | Explain the typical learning to be undertaken by each |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | of these groups. |
| 1:30 - 2:10 | 3. Teaching skill areas in hospice |
| 15 minutes<br>Flip Chart Showing Definitions | Review with participants the matrix of Teaching Skills/Functions in Hospice. Note that the teaching functions you have just described form the horizontal axis of the matrix. The vertical matrix axis consists of those skill areas typically required to perform each of the functions. |
| | Explain the definitions of the teaching skill areas: |
| | ● Briefing - organizing and distilling large amounts of data and information for quick presentation and comprehension |
| | ● Instruction - designing and conducting a learning experience for a specific purpose |
| | ● Facilitation - ensuring discussive participation and interchange on a specific idea/issue/problem by members of a group |
| | ● Monitoring - observing individual or group activity/performance and providing content or process interventions as needed |
| | ● Modeling - demonstrating the behaviors, skill applications and attitudes being transmitted or taught to others |
| | ● Team building - defining roles and interactions among group members in consideration of group and task needs |
| | ● Feedback - delivering specific observations about behaviors and their effects upon others |
| | It is very important that the participants realize that these are skills they may have developed and used in settings other than the teaching situation. For some, these skills are used in the process of raising children and managing a family; for others these skills may have been used in community, church, political, professional, etc., groups |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 5 minutes | Ask the group to think about one of the skill areas just defined and to list as many different settings as they can in which they have used the skill. |
| or | or<br>GROUP EXERCISE |
| 20 minutes | Divide participants into small groups and appoint a recorder.<br>Assign one or two skill areas to each group and ask the group to brainstrom all of the settings or different ways they have used this skill.<br>Allow 5 minutes for each brainstorm.<br>Ask the group recorder to report the work of the small group. Allow 3-5 minutes for each report out.<br>(Facilitator's note: Deciding whether to use a thought question to the group or the exercise should depend upon your perception of the level of group comfort with teaching. For some groups and individuals, who may not have been exposed or required to perform teaching functions, or for those convinced that they do not do them well, it is advisable to use the group exercise to increase the force of the point that these skill areas are neither mysterious nor esoteric, and that most of us use them unconsciously all the time. For groups that seem at ease with the notion of performing teaching functions in hospice it is sufficient to simply ask them to think about the question. When in doubt, ask the group about their level of comfort and decide based upon their feedback to you.) |
| 10 minutes | Following the thought question/exercise, return to the matrix.<br>Ask participants if they can think of any teaching situations that do not appear on the matrix. If there are additional or unique siturations, add them and instruct participants to do the same with their copy of the matrix. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Analyze the meaning of the matrix, based upon the suggested points on pages 7-8 of the background reading. Note particularly that:<br>• The modeling skill is used across the matrix in all teaching situations |
| 5 minutes | Ask participants if they agree/disagree. Why does the modeling skill seem to be so important? |
| | Responses should include that modeling provides credibility for what is being learned and consistent reinforcement of the learning itself. |
| | Note also that:<br>• Instruction is also needed in several hospice teaching functions, and that this particular skill area is the one to be addressed later in the submodule when participants will have the opportunity to prepare and present an instructional experience for their colleagues<br>• The interdisciplinary team teaching function is probably the most demanding and requires the most skills, and that this particular function will be covered in more detail in a later module |
| 5 Minutes | Ask participants if they agree/disagree. Why is the interdisciplinary team function the most demanding? What other hospice teaching functions appear as more or less demanding to the group? |
| 2:10 - 2:35 | 4. Teaching in the small group setting |
| 20 minutes | Develop a lecture based upon the material and ideas presented on pages 8-11 of the background reading. |
| | Note especially that:<br>• One of the most prominent facts about the hospice teaching functions is that they tend to take place in small groups |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • The dynamics of small groups are very important to the learning process and involve two elements: content and process |
| | • It is the process element with which most instructors have difficulty |
| | Explain the basic typologies of group process stages. Particularly for the learning group of the patient/family, it is important that participants understand that they are not working with a new group, but that families often have long-established ways of functioning and clearly defined roles that may support or inhibit learning. The dynamics of family interaction will be more fully explained in the later module in family counseling, but for the purposes of discussion here, it is probably sufficient to note that some families learn together quite functionally, others do not. Extreme sensitivity is required here: the nurse may need to consider a number of creative options, such as working with another staff member and dealing with two families together, or calling in additional help from a staff member with interest and expertise in working with dysfunctional families. |
| Flip Chart of Group Stages<br>&<br>Stages, Needs & Skills | Review the chart that shows the stages of group development, the typical needs associated with each stage and the typical teaching skills that respond to those needs. |
| | Note especially that: |
| | • The key to effective teaching in the small group setting is that the needs of the group, and not those of the instructor, are foremost |
| | • The assumption with which small group teaching is approached is that the ultimate intent of the instruction is to enable the group to function on its own, to define and negotiate its own needs and methods of accomplishment |
| | • These points may require some sacrifice of the teacher's control over the group in order that the group's capabilities to act on its own can be tested and established |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | (Facilitator's note: The idea of the learner's needs being paramount and the idea of giving over control to the group may be difficult for participants to grasp, as it runs contrary to many people's images of the teaching/learning process. For some participants the issue may be one of clarity: i.e., how do you know when to give over control to the learning group? The ability to make that judgment comes only with practice and experience and even the most experienced instructors and trainers find that each time they approach this point of group development, there is a risk and some uncertainty. For others who may find it difficult, under any circumstances, to give up absolute control and who may view this as a kind of dereliction of duty, it is important to stress the dual role of teacher/learner. In hospice, it is critically important that the nurse be in a position of learning from the patient/family or the staff as well as instructing them.) |
| 5 Minutes | Ask participants to think about groups of which they have been a part, e.g. community groups, political groups, church groups, learning groups, working groups, family groups, etc. Ask for volunteers to describe such a group in each of the stages of development, highlighting:<br>• What group members did?<br>• What the individual did?<br>• How the instructor/leader handled interactions? |
| 2:35-- 3:10 | 5. Teaching style |
| 30 minutes | Develop a lecture based upon the materials and ideas on pages 11-14 of the background reading.<br>Note especially that besides the nature of groups and group process, an equally important variable is the way in which the instructor is perceived and the personal style with which the nurse/teacher sponsors learning.<br>Procure copy of the Integro, Inc. matrix of personal styles (copy not included herein) from Interpersonal |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

Growth Systems, Inc., 640 East Grant St., Minneapolis, Minnesota 55403.

Ask participants to think about people they have known or worked with who might be described as having each of the four styles:

- Promoting
- Supporting
- Analyzing
- Controlling

Ask them to brainstorm together the bahaviors and characteristics associated with each.

(Facilitator's note: You may have to begin this process by providing a description of one of the styles. The prototypical "promoting style" person might, for example, be Professor Harold Hill, the major character in the play and film "The Music Man." Begin with positive statements about characteristics and behavior such as: enthusiastic, full of ideas, energized, capable of organizing and energizing others, etc.).

Once the group has characterized each of the styles, explain how those characterizations change when, for example, an analyzing style looks at a promoting style. Note especially that:

- Each of the 'positive' characteristics becomes negative in connotation: enthusiasm is seen as overpowering, the many ideas seem empty and the promoter incapable of following through, etc.

Ask the group to brainstorm together the characteristics that each style would see in the others. Note that most of the positive descriptors will become negative.

(Facilitator's note: This exercise is usually a fun one for participants in that it constitutes a 'safe' opportunity to negatively describe the behavior and styles of people they have known or with whom they have worked.)

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

Explain the following points in summarizing the use of the matrix:

- The matrix does not address the issue of competence, only the style with which people work, teach and interact
- Each style has its own strengths and weaknesses
- Each style is perceived, i.e. the styles are not judgements about character but rather observations about observable behavior and attitudes conveyed to others during communication
- These observable behaviors can be changed quite deliberately when it is important to work or get along with those of other styles
- We each have a preferred style, or a style with which we are most comfortable and it is very important to take responsibility, in the teaching situation, for the way in which we are perceived by others
- Once that responsibility is taken, the challenge is to determine or sense group needs and to operate in the style that is most conducive to their learning

(Facilitator's note: Some participants may be curious about how preferred styles are determined. The Integro, Inc. matrix was developed as a descriptive tool with which to work on the mangerial styles of administrators and has been adapted to teachers. The technical process involved when Integro, Inc. works with managers or teachers is as follows: managers or teachers provide a list of 3-5 colleagues whose judgment they respect and trust; these people then answer a series of questions about the working style they perceive using a language differentiation instrument; responses are analyzed by computer and appear as a placement on the matrix.)

Ask participants where they see themselves fitting into the matrix and what they see as their preferred style.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Ask participants to think about a situation in which they altered that style, considering:<br>● Why they altered?<br>● How they did it?<br>● What the results were? |
| 5 Minutes | Ask for volunteers to describe their situations. Note the importance of reinforcing the idea that changing styles does not mean that the individual is somehow weak, or a chameleon. Remember that the matrix descriptions should not be construed as having implicit value judgements and that they are only descriptions of behavior. The important point about the matrix and this discussion is that personal style can influence the group learning process, and in keeping with our goal of sponsoring learning, rather than meeting the personal needs of the instructor, we can/must be able to alter styles. |
| BREAK (5 minutes) |  |
| 3:15 - 3:30 | 6. Learning environment and assumptions |
| 15 minutes | Develop a lecture based upon the material and ideas on pages 14-16 of the background reading.<br>Note especially the importance of the learning environment.<br>Ask participants to think about the environments in which they learn or have learned best. These should not be limited to 'school' or institutional settings.<br>Ask for volunteers to describe their preferred learning environments. |
| Flip Chart Showing Assumptions | Explain the assumptions that can be made about adult learners:<br>● Need to learn - people will learn what they think they need to know<br>● Clear expectations - people need to know what |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | is expected of them and what the rewards for participating and learning are |
| | • Climate of safety - people need to feel comfortable whether at home or in a hospice; they need to feel comfortable asking questions and need to feel able to test and fail without losing face/status |
| | • Supportive feedback - people need to practice new skills and test new ideas, and they need to know how well they did and what needs more work |
| | • Confidence in teacher/instructor - people need to feel that the teacher/instructor understands the content as well as the process of what is being learned |
| | Ask participants to review the matrix of hospice teaching functions and skills. Ask what assumptions they can make about learners in each of the functional categories. |
| | (Facilitator's note: Responses should include such insights as the inherent stress, fear, sadness, associated with families when they are referred to hospice and need to begin learning about hospice care, about their role on the care team and about death, dying and grief.) |
| | Ask participants to describe how they would accommodate these needs. How would they structure the environment? What style would they use? What teaching skills? |
| 3:35 - 3:40 | 7. Instructional techniques |
| 5 minutes | Develop a lecture based upon the material and the form presented on pages 16-19 of the background reading. |
| 3:40 - 5:00 | GROUP EXERCISE |
| 150 minutes<br>(Continued) | Divide the group into two subgroups. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| and<br>8:00 - 8:30<br>or<br>3:40 - 6:10 | Instruct each participant to choose one of the hospice teaching functions and to use the form to plan a five minute learning experience on any topic, issue or care technique with which they feel comfortable<br>Allow 20 minutes for individual preparation. Assist participants as necessary.<br>Convene the two subgroups. Select order of participants to make their presentations to the group.<br>Allow five minutes for each presentation and an additional five minutes for feedback to the presenter from the group. |
| Discussion<br>8:30 - 8:40 | Reconvene large group. Discuss participant's experiences and insights in preparing for and delivering their learning experiences. |
| Review & Closure<br>8:40 - 8:45 | Review submodule content areas, stressing the application of communication skills to the teaching functions of the hospice nurse and its importance.<br>Respond to questions.<br>Close session. |

## SUBMODULE B LECTURE

## APPLYING COMMUNICATION SKILLS TO HOSPICE TEACHING FUNCTIONS: BACKGROUND READING

### I. UNDERSTANDING THE TEACHING PROCESS

Most of us have an image of what "teaching" is all about based upon our long experience, not as teachers, but as learners. For most people, those images begin with a classroom, chairs neatly arranged and students in defined rows. Part of the image is usually a teacher or an instructor, placed at the front of the room, clearly in authority, making didactic presentations and giving objective tests.

In thinking about teaching in the hospice care setting, it is very important that we establish a more dynamic image and definition of teaching. In many teaching situations we seem to be able to tolerate the fact that learners are alienated, that they may not, in fact, be learning what we want them to learn. Consider again the image of the traditional classroom, the kind in which most of us received basic instruction in public or private schools. There were then and are now a number of motives or concerns in the structuring of education, from the elementary grades to graduate schools. In the early years, what seems to be at least as important as the acquiring of fundamental skills in language and arithmetic is the learning of accepted social norms and standards. Throughout most of childhood education, we are socializing children in the basic rules and recipes for interaction and social activity. Despite the recent attention given to basic skills education, there are few who would deny the multiplicity of functions in childhood and adolescent schooling. We expect that schools, within the thirteen years normally given over to this purpose, will teach children not only the skills of literacy and functional mathematic proficiency, but also will provide basic understandings of social relationships, of bodily exercise and health, of citizenship and the like. With all of these complex motivations for instruction, and given the compulsory nature of childhood education, it does not seem too surprising that some learner alienation is tolerated. How much is tolerated is perhaps highlighted by the overall declines in college entrance examination scores over time, reinforced by the inflation of grades and the lowering of basic skill requirements. In the teaching that will take place in the hospice care setting, however, the learning tasks are so crucial and so directly fundamental to the goals of appropriate death and care of the dying and their families, that we can ill afford to tolerate alienation from the learning process. Unlike pedagogy, or the education of children, we have neither the time nor the complexity of motives to unnecsarily complicate the learning process: hospice teaching must be direct, goal-oriented and responsive to learner needs.

We can draw further distinctions between the teaching in hospice and the processes of andragogy, or the teaching of adults. Most of you have, by now, been exposed to the teaching of adults that takes place in the college, university or professional school setting. In these settings, the instructional process is more directed, at least in theory, toward skill development and increasing of the knowledge base. Still, there are other motives, especially in professional education that include the enforcing of accepted standards and the limiting of the numbers of persons entering the field. In addition, there are few post secondary degree holders who would argue with the notion that at least one of the major things learned and tested in graduate and professional schools is simple endurance and the ability to function under pressure. In the hospice care setting, teaching will not involve the element of competition and artificial stress that characterizes much of the traditional and structured teaching of adults. Teaching must be successful without the threat of exclusion that is implicit in much graduate and professional education; and there is little room for unnecessarily stressful learning when the inherent stresses of involvement in in hospice are considered.

Thought Question:

> Consider the situations, as adults and as professionals, in which you felt you have done your best learning. What was the environment? What were your needs/expectations? What was the role of the person instructing you? What were the most important things that made your learning successful? Or, if you can't think of a positive learning situation, consider a negative one answering the same questions. What were the most important things that made the learning unsuccessful?

## II. TEACHING FUNCTIONS IN HOSPICE

We have generally discussed the ways in which the nurse's teaching roles in hospice care differ from traditional images of teaching and learning. At this point it is important to consider precisely what those teaching roles in hospice are, and, subsequently, what kind of skills they demand.

Discussion Question:

What kind of teaching roles to you see in hospice care?

There are three principal learning audiences with whom hospice nurses must be concerned:

- The patient/family
- The interdisciplinary team/staff
- The community

Clearly, the patient and the family come first, for their tasks are foremost in hospice: They need to learn about hospice, about their roles on the care team; they need to understand the processes of death, dying and grief; they may need to learn very specific care techniques; and some families may have to learn how to communicate clearly and effectively with each other and with you.

The interdisciplinary team also has important learning tasks: Members must learn about specific cases and people brought to the group's attention; they need to learn how the presenter, often the hospice nurse, wants and needs their assistance and advice; and, in some cases, the interdisciplinary team may need to learn how to function as a working group, how to settle issues of authority, discussion process, consensus and difference, etc. The hospice staff, including new and incoming nurses, volunteers and others may also need to learn much about the hospice setting, what the expectations are for their roles and performance, how to request and receive help, as well as the general matters of the policies and operating procedures of the hospice itself.

The community, too, has a learning role. Because hospice is a relatively new concept in health care, the communities in which they operate need to learn about the setting and service, about its availability and intent. For those hospices in which members of the health and human service community may be sought out to bring specific kinds of expertise to the hospice, i.e., nutrition specialists, social workers, legal advisors, etc., there is a teaching role involved in recruiting and retaining such specialized help and volunteers.

Not all of these teaching functions, of course, will be carried out by every hospice nurse, but the range of these functions within hospice is very significant and most hospice nurses will be called upon to perform at least some of them. To review, the major teaching functions in hospice are:

- Teaching the patient and the family about hospice approaches and their role in the care team
- Teaching the patient and the family about the process of death, dying and grief
- Transmitting specific care techniques to the patient and the family
- Modeling and transmitting communication skills to the patient and the family
- Participating in and orienting the interdisciplinary team to patient/family status
- Teaching and orienting new hospice nurses, other staff and volunteers to hospice programatic and care issues
- Teaching and orienting other community support agencies to the programatic and care functions of hospice

## TEACHING SKILLS/FUNCTIONS IN HOSPICE

| FUNCTIONS / SKILLS | Patient/ Family: Hospice care | Patient/ Family: Death, Dying & Grief | Patient/ Family: Care Techniques | Patient/ Family: Communication Skills | Staff/Nurses: Hospice, Care & Communication | Interdisciplinary Team: Patient Family Status & Communication | Community Hospice |
|---|---|---|---|---|---|---|---|
| Briefing | ● |  |  |  | ● | ● | ● |
| Instruction | ● | ● | ● | ● | ● |  | ● |
| Facilitation | ● | ● |  | ● |  | ● |  |
| Monitoring |  |  |  | ● |  | ● |  |
| Modeling | ● | ● | ● | ● | ● | ● | ● |
| Team-Building |  | ● | ● |  |  | ● |  |
| Feedback |  | ● | ● | ● | ● | ● |  |

## III. TEACHING SKILL AREAS IN HOSPICE

To further our understanding of the teaching functions that the hospice nurse is called upon to perform, it is important to consider each of those functions in terms of the skills necessary to perform successfully. The chart below provides a matrix to describe which teaching skill areas are inherently required in the hospice teaching functions we have identified.

It is important to consider some common definitions for each of these skill areas:

- Briefing

  Organizing and distilling large amounts of data and information for quick presentation and comprehension

- Instruction

  Designing and conducting a learning experience for a specific purpose

- Facilitation

  Ensuring discussive participation and interchange on a specific idea/issue/problem by members of a group

- Monitoring

  Observing individual or group activity/performance and providing content or process interventions as needed

- Modeling

  Demonstrating the behaviors, skill applications and attitudes being transmitted or taught to others

- Team Building

  Defining roles and interactions among group members in consideration of group and task needs

- Feedback

  Delivering specific observations about behaviors and their effects upon others

In defining each of these skill areas, we are trying to place a consistent meaning and a precise term on things that most of you do all the time in work, family and other settings. Clearly these are not mysterious or esoteric skills.

Discussion Question:

> Think about one of the skill areas we have just defined. How many different settings or different ways have you used this skill?

(Or Group Exercise)

> Divide participants into small groups and appoint a recorder. Assign one or two skill areas to each group. Ask group to brainstorm all of the settings or different ways they have used this skill. Allow 3-4 minutes for each brainstorm. Ask the recorder to report the work of the small group. Allow 5 minutes for each report out.

To return to the matrix for a moment, we need to look at how the skill areas are employed in and across hospice teaching functions. Note, for example, that "modeling" (or demonstrating the behaviors, skill applications and attitudes being transmitted or taught to others) is the single most consistent skill across all hospice teaching functions.

Discussion Question:

> Do you agree/disagree? Why does modeling seem to be so important?

The modeling skill is important for many reasons, but principally for credibility and reinforcement. Adult learners tend to learn best when they work with an instructor they find credible. Having, for the most part, lost the ingenuousness of children, adult learners often want behavioral and other signs that they are learning from a competent source of information. If, for example, a care technique or a communication skill is being explained that the instructor cannot or does not perform well, the learning process will often be halted and the learners quickly panic. A second importance of the modeling skill is in the fact that for adults, in learning new information and skills, hearing about them is seldom enough. Each time the instructor models the application of knowledge, the skill or attitude, a reinforcement of the learning takes place.

Note also that instruction (or the designing and conducting of a learning experience for a specific purpose) is also needed in several hospice teaching functions. For many people who have not worked with educational theory or technology, this can be among the most intimidating of the teaching skills. Later in this submodule, we will work with the instructional skill area and provide some tools for helping you quickly formulate learning experiences.

Looking at the matrix from another perspective, note that it is the function of the interdisciplinary team that seems to be the most demanding one and the one that requires the largest number of skill areas. In a later module of this course the role and function of the interdisciplinary team will be covered separately.

Discussion Question:

Do you agree/disagree? Why is the interdisciplinary team function the most demanding?

What other hospice teaching functions do you see as more or less demanding?

## IV. TEACHING IN THE SMALL GROUP SETTING

One of the most prominent facts about the hospice teaching functions we have described is that they tend to take place not on an individual basis, but rather in the group setting: patients and their families, groups of staff, the interdisciplinary team, community members. Since the small group seems to be the most common unit of learning with which you will be working, it is important to consider some of the aspects of learning groups that will determine how you apply the teaching skills we defined.

There are a number of prominent and accepted theorists about the group learning situation who place great emphasis upon communication. Alfred Gorman, for example, explains two crucial aspects of group learning: content (the topic under discussion) and process (feelings about oneself and others during learning communication). "The process level," Gorman writes, "is often more hidden and more subtle than the content level. People generally have great difficulty in communicating feelings (especially) in a group setting...problems...arise between people on the feeling level...and...influence the quality of learning and teaching..." (Gorman, 1974). Gorman concluded that the importance of learning content and process could not be underestimated: "The improvement of teaching," he argues, "is directly related to the improvement of communication on both...(the content and the process) levels. Because one level is inter-related with the other, the bypassing or ignoring of the process level creates a more serious impediment to learning than has been realized until recent years." (Gorman, 1974)

In any group learning situation there are two key elements: content and process. The content is what is being learned and taught; the process is how the learning is taking place. From this notion flow three key points of importance in hospice teaching functions:

- Groups go through changes or stages of development
- Content of learning needs to be responsive/reflective of those stages
- Teaching style or skill needs to be responsive/reflective of those stages

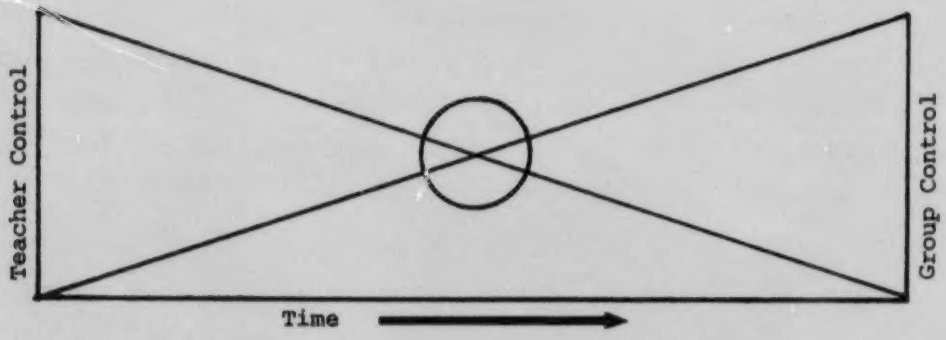
There are many ways to describe the changes that groups go through, but one of the easiest to remember and most useful is that they, ideally, pass through three stages:

| | | |
|---|---|---|
| STAGE 1 | Dependence | (infancy) |
| STAGE 2 | Testing | (adolescence) |
| STAGE 3 | Conjoint Functioning | (maturity) |

These stages can, in many ways, be compared to the stages of human personality development, for there are many similarities. Like infants and small children, groups initially exhibit dependency on the instructor or teacher for guidance in learning. It is important to remember that families, for example, are not "new" groups: they have established roles and routines of behavior, the nature and importance of which will be explained more fully in the module on family counseling. But, they are assembling, in the hospice situation, for what is often a completely new experience and purpose. As such, they will need to know what they are there for and what is expected of them before they can begin the process of learning how to interact with, support and help the dying family member as a part of the hospice team. Groups in the second state of testing, or adolescence, are exploring the limits of authority and their potential as a group. As with older children seeking definitions of self and relationship to others in the world around them, groups will often test the instructor's authority in a variety of ways including argumentation, silence, disruptive behavior, withdrawal and the like. Groups in a mature phase can decide upon their needs and can accomplish their fulfillment, can function together and can sublimate some individual needs in the interest of the group. As effective teachers and instructors, we need to understand and meet these group needs in their various stages. Consider again the stages of group development, this time with the addition of what groups in each stage need from the teacher/instructor and what skill areas are involved in meeting them:

| STAGE | CHARACTERISTICS | NEED | TEACHING SKILLS |
|---|---|---|---|
| 1 | Dependence (infancy) | orientation<br>information<br>expectations setting | briefing<br>instruction<br>modeling |
| 2 | Testing (adolescence) | questions/answers<br>disclosure<br>skill development<br>practice | instruction<br>facilitation<br>feedback<br>modeling |
| 3 | Conjoint Functioning (maturity) | autonomy<br>problem solving | monitoring<br>feedback<br>modeling |

Note that the teaching roles and skill areas employed change to meet altering group stages and needs. Another way to visualize these changes is as follows:



We are operating here on the assumption that the goal of the interaction between the teacher and the learning group is ultimately that the group will be able to function independently to define and meet its own needs. Note that, therefore, teacher control of learning goes down over time with group control moving up. There is often a very difficult moment in the learning process, shown as the circle, where the two control lines meet and in which the balance shifts from teacher to group. This can sometimes be a dramatic shift, involving a kind of confrontation between the group and the instructor and at other times it is a natural progression and subtle shift.

These group stages are not unique to hospice, nor to teaching.

Discussion Question:

> Consider groups of which you have been a part, e.g., community groups, church groups, learning groups, working groups, etc. Describe one in each stage of development. What did the group members do? What did you do? How did the instructor handle changes?

## V. TEACHING STYLE

In considering teaching skills as a specialized application of communication skills, it is important to note that teaching, like communication, is not purely a matter of technique but also involves us individually in terms of our personality components and personal style. An important part of the teaching we have been describing throughout this submodule is the understanding and flexibility to perceive and respond to group needs. Equally important is a knowledge of yourself and how you are perceived by others: the impact of your teaching style will be determined both by techniques applied and by the style with which they are applied.

The following matrix details four of the most commonly perceived styles of personal interaction. These styles can be seen in the workplace, at home, as well as in the teaching situation. The matrix is composed of two range variables that result in behavior that is readily observable: dominance --- subdominance and informality --- formality. The matrix roughly defines four quadrants: persons with dominant and informal styles tend to be perceived as "promoting," those with subdominant and informal styles tend to be seen as "supporting." People who tend to be subdominant and formal are often seen as "analyzing" and those who are formal and dominant are viewed as "controlling." These are, of course, gross distinctions and they deserve a closer look.

Discussion Questions:

> Think of someone in your experience who you would describe as "promoting," i.e., exhibiting dominant but informal styles of communicating. What behavior or characteristics do you associate with this person? What about a supporting person? An analyzing person? A controlling person?

It is important to keep in mind that these are not value judgments, but are descriptors for behavior and styles of communicating. The matrix does not address the issue of competence, or skill, only of the style with which work and communication take place. Now look at the matrix from a different angle: imagine that a person with an analyzing style is looking at the behavior of one with a promoting style. The analyzer is likely to see all of the strengths of the promoting style as weaknesses: the enthusiasm of the promoter is seen as overpowering; the many ideas generated by promoters are seen as empty thoughts with no follow-through; the cheerfulness is seen as unrealistic optimism. Or, imagine the controlling person looking at a supporter: most likely, the supporter will be seen as weak and wishy-washy. The supporter, on the other hand, viewing the controller, will tend to see a patriarch/matriarch and a person closed to the influence of others, an egotist.

Discussion Questions:

> How do you imagine that people in each of the quadrants would view the others?
>
> Why are these perceptions important? Or are they?
>
> Describe teachers or instructors in your experience who fit into these general categories. How did you react to them?

The significant point about this matrix is not that each of us tends to have a preferred style of communicating, teaching and working. We do. However, the point here is that other people perceive us differently depending upon their styles, and their perceptions are based upon our exhibited behaviors and attitudes. And, most important of all, those observable behaviors can be altered when we take responsibility for the way in which we are perceived and when we alter our behaviors to conform with the needs of the people learning from us. The most effective teachers, as well as the most effective supervisors and administrators, are those who are capable of altering their styles of communication to fit varying needs and situations.

Clearly, our style of communicating and teaching, our style of behavior, can enhance or clash with the learning needs of the group. We all have preferred styles, but we all have the capability to flex, to alter those styles. And, given that the purpose of the teaching functions in hospice is to further the patient/family's goals and needs rather than our own, this ability to be flexible is critically important.

Discussion Questions:

Where do you see yourself fitting into the matrix?

Where is your preferred style?

Think about a situation in which you altered that style. Why did you do it? How did you do it? What was the result?

## VI. LEARNING ENVIRONMENT AND ASSUMPTIONS

Because hospice teaching functions involve so many different groups, i.e., many family groups, the staff, the community, it is important to consider some of the variables besides group development and instructor style that can support or diminish learning. The learning environment is clearly one of those.

Discussion Question:

Consider the environments in which you learn best. Include every factor you can think of, e.g., instructor style, room size, lighting, etc. Describe.

Because of the nature of hospice care and because of the number of teaching functions that involve hospice families, there are several environmental factors that need special consideration. For example, in teaching patient care techniques, it is very important to make sure that the learning environment includes the equipment that the patient/family will ultimately use. Learning a care technique with one piece of equipment, only to find that when it is purchased, it looks, feels and may operate slightly differently can threaten the learning process and the comfort level that patients/families feel with providing home care. It may also be important to consider the home environment as the site for teaching certain techniques to improve, again, that level of comfort and familiarity patients/families need as they cope with home care for the dying. Sometimes, being able to carry out hospice teaching functions in the home is very possible; other times it is not and may require referral to other community home care agencies. Another environmental factor that can sometimes inhibit learning is that of culture/language. Particularly for hospice families with culturally established and inviolate sex roles and for those for whom English is a second language, there can be interferences with all of the learning processes the hospice nurse is creating. Sensitivity to these and flexibility in working with and through them is extremely important to the goals of hospice and may require calling in additional resources such as translators or bi-cultural/bi-lingual professionals or volunteers.

In general, there are several assumptions that can be made about adult learners:

- Need to learn

  People will learn what they think they need to know

- Clear expectations

  People need to know what is expected of them and
  what the rewards for participating and learning are

- Climate of safety

  People need to feel comfortable in the learning environment, whether at home or in a hospice; they need to feel comfortable asking questions and feel able to test and fail without losing face/status

- Supportive feedback

  People need to practice new skills and test new ideas, and they need to know how well they did and what needs more work

- Confidence in teacher/instructor

  People need to feel that the teacher/instructor understands the content as well as the process of what is being learned

Discussion Questions:

Look at the matrix of hospice teaching functions and skills. What assumptions can be made about the learners in each of the function categories? How would you accommodate them?

## VII. INSTRUCTIONAL TECHNIQUES

In all of the teaching skill areas we have defined and discussed, the most important factor in being able to perform them, is practice. We noted that most of us use these skills in many settings and have used them over much of adult life. But, among those skills is one that can be assisted with some simple tools: instruction. In designing and conducting learning experiences for specific purposes, it is essential to be clear and organized to be at once cognizant of what the group needs to learn and how best it should be taught. It is often helpful to make each of these things explicit by writing them out. The form on the following page was designed to assist you in doing that.

First, consider the learning group: What is its stage of development? What are the ages and attention spans of the learners? What are their verbal abilities? Motivations? Expectations? Are there any cultural, language or other factors of importance?

Then, consider what it is they need to learn. Most often the learning group needs to learn several things, e.g., several care techniques, a new idea or perspective on death, new information about the process of dying being experienced by the patient, etc. It is best to separate these and identify each one alone.

Given the learners and what they need to learn, consider next the best methods for assuring that the learning takes place. Should information or ideas be presented in a briefing? Is there a new skill to be learned that will require some practice and supervision? If so, how well do they have to perform it and how long will the practice take? Will the group need to discuss information or ideas? In short, all of the teaching skills available to the hospice nurse must be considered and weighed against the needs of the group and the learning they must accomplish.

Finally, what will the nurse watch for and how will the nurse know that the teaching function has been accomplished and the learning has taken place. It is important to keep what we might call instructional case notes, remarking about what worked well and what didn't with specific families and groups. This kind of informal evaluation is helpful as a reminder next time the group has instructional needs, but is also exceptionally important in the event that staffing patterns for families change and another nurse or staff member must pick up and carry out the instructor role.

Experienced instructors have found that, eventually, the thought process that the form prescribes becomes intuitive and natural. Like all tools, it can be altered and revised as it is used, and for some people it ultimately becomes unnecessary except as a reminder with new groups to consider all of the important variables.

GROUP EXERCISE:

Divide the group into two subgroups. Instruct each participant to choose one of the hospice teaching functions and to use the form to plan a five minute learning experience on any topic, issue or care technique with which they feel comfortable

Allow 20 minutes for individual preparation. Assist participants as necessary

Convene the two subgroups. Select order of participants to make their presentations to the group

Allow five minutes for each presentation and additional five minutes for feedback to the presenter

Reconvene large group. Discuss participants' experiences and insights in preparing for and delivering their learning experience

| LEARNING GROUP CHARACTERISTICS | LEARNING OBJECTIVE | METHODS | EVALUATION |
|---|---|---|---|
| Stage<br>Needs<br>Motivation<br>Others<br>Cultural Language<br>Environment | What should they learn?<br>How well do they need to do it? | Given the group and the learning objective, how should the learning take place?<br>- environment<br>- role<br>- practice<br>- time | What seemed to work? Why?<br>What didn't? Why?<br>What needs to be changed? |

| LEARNING GROUP CHARACTERISTICS | LEARNING OBJECTIVES | METHODS | EVALUATION |
|---|---|---|---|

# MODULE III: CONCEPTS OF DEATH, DYING, GRIEF AND LOSS

FACILITATOR MANUAL

DEVELOPED BY:

Therese A. Rando, Ph.D.

# MODULE III: CONCEPTS OF DEATH, DYING, GRIEF AND LOSS

## I. PURPOSE:

The purpose of this module is to assist the nurse in understanding the processes of grief in reaction to loss and developing effective treatment interventions for dying patients and those that are left behind.

## II. CONTENT:

The module content includes the following topics:

### Section A: The Impact of Philosophical and Cultural Attitutes Towards Death

- The impact of death on life
- Cultural attitudes towards death and the variables that have influenced them in America

### Section B: Grief: The Reaction to Loss

- Definition of terms
- Types of loss
- Theories of grief
- "Grief Work"
- Specific reactions to loss
- Manifestations of grief (psychological, physiological and social)
- Forms of grief reaction
- Factors influencing grief (psychological, physiological and social)
- Abnormal grief
- Factors influencing abnormal grief (social and psychological)
- Symptoms and behaviors of abnormal grief
- How to help the griever
- Wakes, funerals and other mourning rituals
- Grief and children

## Section C: The Dying Patient

- Death as a unique crisis situation
- Tasks of the dying patient
- Grieving and fears of the dying patient
- Defense mechanisms of the dying patient
- Variables influencing the response of the patient
- The issues of acceptance, withdrawal and detachment and hope
- The concept of "appropriate death"
- The nurse-patient relationship when the patient is dying
- Helping the dying patient
- Death across the life cycle: identity tasks, conceptions of death and issues as a terminal patient

## III. LEARNING OBJECTIVES

- Identify four modes with which people provide themselves with a sense of immortality
- Define "grief", "mourning" and "bereavement"
- Define the two types of loss and give two examples of each type
- Define the three tasks of "grief work"
- Identify the three general phases in the psychological manifestation of grief
- Identify at least four of the physiological manifestations of grief
- Identify at least three psychological factors influencing an individual's grief reaction
- Define "anticipatory grief"
- Identify at least five symptoms indicative of unresolved grief
- Identify and describe at least three social and psychological factors influencing an individual's failure to grieve
- Identify at least three ways to help a griever

- Identify at least four things not to do in helping a griever
- Identify at least two "fairy tales" told to children about death and the harmful effects of each
- Identify at least three things to do when telling a child about the death of a loved one
- Identify at least four tasks of the dying patient
- Identify the four types of death an individual undergoes
- Identify at least three emotional reactions to facing one's own death
- Identify at least four fears of the experience of dying
- Identify the three types of defense mechanisms used by terminally ill patients and give an example of each
- Define and identify the four criteria of an "appropriate death"
- Identify the three levels of understanding toward which communication with the terminally ill patient should be directed
- Identify at least three responsibilities of a caregiver in working with the terminally ill patient
- Identify at least four ways in which to help the patient have a better death
- Identify at least one identity task, conception of death and issue as a terminal patient for each of the seven age groups across the life cycle

## IV. PERSPECTIVE

The participant manual is divided into three sections. Section A is designed to acquaint the participant with the impact on our lives of our knowledge of our own mortality. It seeks to clarify how our response to death influences our response to life. It attempts to foster the participant's own examination of death attitudes and feelings in order to make the participant more aware of them as determinants of lifestyle and manner of working/relating with dying patients.

Also included is a section designed to provide the participant with a cultural framework for interpretation and appreciation of the American individual's response to death. Religious, cultural, ethnic and social norms and proscriptions are discussed as influential variables in providing structure and perspective to individuals. The impacts of a death-denying attitude and the factors which have fostered it in our society are addressed as further variables of the social-philosophical matrix from which an individual's response to death arises.

Section B is the most critical. It focuses on the issues, processes and dynamics of loss. The topic of loss is taken as the main issue in this and the succeeding sub-modules. If the participant can grasp the concepts within this sub-module, then the issue of the dying patient is understandable as a unique aspect of the same situation of loss. It is hoped that the instructor will continually make this point and will illustrate how grief is a natural reaction occurring in response to all losses, not relegated solely to a reaction after death. In this way other losses of patients will be able to be understood by the participant as involving grief processes and requiring conceptualization of them as such, with a consequent response based on therapeutic interventions appropriate for a griever. The issue of children and death is discussed with respect to the similarities and differences between adult and child responses to loss.

Section C focuses on the unique situation of the dying patient. It is presented within the framework of a loss experience, with the idiosyncratic difficulties and processes of dying delineated. Continual attention is paid to therapeutic intervention and the nurse-patient relationship in an attempt to foster a "mind set" for communication and interaction between the participant and subsequent patients.

Also included is a section designed to provide the participant with an appreciation of the changing issues and conceptions of death across the life cycle. The purpose of this is to illustrate how one's response to death and loss reflects the important issues in life at that particular time. In this way, death and the reaction to it are intimately involved with the individual's life-as-a-whole. Contrary to some recent attempts at approaching death, it must be understood within the context of the individual's life and cannot be separated from it artificially in order to study it as if it actually were an independent or self-contained topic/issue/process for the individual.

## V. STAFF REQUIREMENTS

The module can be presented by one instructor. Due to the sensitive nature of the topics and the exercises in the sub-modules, it is expected that the instructor possess not only an ability as a group facilitator, but have had advanced training in clinical intervention, knowledge of personality and psychopathology and experience with dying and bereaved individuals. It is not uncommon to have this module prompt some emotional response in an individual which would need to be recognized and worked with therapeutically by the instructor (e.g., in terms of referral to treatment; closure of a situation which is inappropriate to be handled in an educational group; and legitimization of some anxiety, to name but a few possible instructor responses). Additionally, this advanced training and experience is required because of the interventions discussed within the module which will need further explanation and/or clarification by an instructor who has had some experience in the areas of counseling and communication/listening skills training.

The second major requirement for the instructor is a sound familiarity with the literature in death, dying, loss and bereavement. A thorough theoretical knowledge base must necessarily be possessed by the instructor. Unlike many other topics, the instructor of this module will need much more background information than that presented in the module in order to effectively teach this module and be helpful to the participants.

The third major requirement is that the instructor has started to come to grips with his/her own mortality. This process need not necessarily be completed, but the instructor should be one who can cope with and recognize the impact of death and its implications on him/herself.

In summary, the facilitator should have experience in the areas of counseling and working with dying or bereaved individuals. The instructor must have an in-depth familiarity with the current literature and research on the topics of death, dying, loss and bereavement. The instructor must have started to come to grips with his/her own mortality and be aware of its impact upon the self.

## VI. SPACE REQUIREMENTS

There should be enough room for comfortable seating of all participants. Ideally, a room conducive to group discussion would be best (e.g., where participants can sit in a circle or on the floor rather than in classroom style). However, this requirement is flexible. If there will be small group discussion of the exercises, adequate space must be provided for breaking up into small groups and talking without being too proximal to other small groups.

## VII. MATERIAL NEEDS

Resource paper for participants ("Concepts of Death, Dying, Grief and Loss", by T. A. Rando, Ph.D.). A chalk board or newsprint paper should be available for making note of points brought out of discussion and exercises. Magic markers, chalk, and masking tape will be needed. Name tags should be provided.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | REGISTRATION<br>The instructor should arrive early to greet participants as they arrive and to check for any last-minute adjustments of the physical space (e.g., room temperature, arrangement of chairs, etc.). |
| 10 minutes | WELCOME AND ADMINISTRATIVE DETAILS<br>Purpose:<br>To quickly complete administrative tasks needed to facilitate the training event.<br>Instructions:<br>Following introduction of instructor and introductory remarks, cover the following:<br>• Expectation for active participation<br>• Break times<br>• Restroom locations<br>• Decisions about smoking behavior<br>• Locations of refreshments for break<br>• Eating places<br>• Climate setting (define space of large meeting room and areas where small groups will meet)<br>Inform the group that for several exercises there will be a need for small group discussion. Suggest that they break themselves up into groups of four or five and this will constitute the group to which they will go when the large group breaks up. Strongly urge the participants to place themselves into groups in which they know the fewest number of people in order that it be as novel an experience as possible. Or arbitrarily break groups into smaller units by counting off.<br>Inform the group to feel free to interject questions or comments as they desire. Share with them the expectation that this will be an active, sharing experience as |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | opposed to a passive, didactic one. |
| | SECTION A: THE IMPACT OF PHILOSOPHICAL AND CULTURAL ATTITUDES TOWARDS DEATH |
| | THE ISSUE OF SELF-MORTALITY |
| | Purpose: |
| | To understand the impact of death on one's life and lifestyle. |
| | To start to confront one's own death-related feelings and to use this knowledge to understand how they influence one's life and work with dying patients. |
| | Instructions: |
| 20 minutes<br>Chalkboard and chalk or newsprint and marker | Develop a lecturette based on pages 5-7 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | • Verwoerdt, 1966<br>• Koestenbaum, 1976<br>• Kavanaugh, 1972 |
| 20 minutes | At the conclusion of the lecturette, direct the participants to break down into small groups (or else have them remain in the large group, complete the exercise, and then process it fully). Have them complete Exercise I and share their thoughts and reactions. Have one person serve as a recorder to later report to the large group. Float to each group to facilitate the process and answer any clarifying questions. Following this, reconvene to large group and have reports from each small group. Write down responses on chalkboard or newsprint. Open up floor for discussion or comments. Ask for reactions. |
| | Be sure to tie this exercise in with the reading from Kavanaugh on "Confronting Death-Related Feelings". Stress how it is natural and "okay" to have some negative or anxious feelings about death. The important point is that these be recognized and acknowledged and |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | that their impact on the participant's lifestyle, and attitudes and work with dying patients, be realized and understood. |
| | ATTITUDES TOWARDS DEATH AND CULTURAL/HISTORICAL PERSPECTIVES |
| | Purpose: |
| | To understand that the individual's response to death and loss is strongly influenced by his/her social, cultural, religious and ethnic backgrounds. |
| | To identify the three socio-cultural responses to death. |
| | To orient the participants to the death-denying attitude of the American culture which will have an influence on the American patient's response to death and loss. |
| | To identify the factors responsible for our society's difficulty in dealing with death. |
| | To identify the four modes through which people achieve some form of immortality. |
| | To discover how Hospice can change the American way of death. |
| | Instructions: |
| 15 minutes | Develop a lecturette based on pages 10-15 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | ● Toynbee, 1968<br>● Kübler-Ross, 1969<br>● Feifel, 1971<br>● Lifton, 1968 |
| 5 minutes | Be sure to question the participants as to how they feel that Hospice could change the American way of death. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | SECTION B: GRIEF: THE REACTION TO LOSS |
| | DEFINITION OF TERMS AND TYPES OF LOSSES |
| | Purpose: |
| | To understand the definitions of "grief", "mourning" and "bereavement" and the implications of the definitions. |
| | To appreciate that loss takes place constantly throughout human life. |
| | To identify some of the losses inherent in being hospitalized and having cancer. |
| | To understand that losses may be physical or symbolic and that grief occurs to some extent after all of these losses: it is not relegated solely to after a death. |
| | To underscore how difficult experiences in the participants' own lives are centrally related to loss. |
| | Instructions: |
| 15 minutes | Develop a lecturette based on pages 15-18 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| 15 minutes | At the conclusion of the lecturette, direct the participants to complete Exercise II. Following completion of the exercise, note to them that loss (physical or symbolic) is the basis of the majority of one's problems. Encourage the participants to note their reactions to their own losses in order to prepare them for identifying with dying and bereaved individuals and to illustrate how we all undergo the grief process to a greater or lesser extent in our everyday lives. The goal is to have the participants realize that many of our responses and actions are prompted by some form of loss (physical or symbolic). |
| | Make sure that the participants have a thorough appreciation for the fact that many experiences of loss and grief are not usually identified as such, e.g., moving, divorce, being hospitalized. Because of this, a normal |

grief process (natural after a loss) is often not acknowledged or legitimized. People often do not recognize they have sustained a loss and need to identify it as such and grieve appropriately for it. Therefore, stress the concept of symbolic loss in order to make these points. Have the participants list some examples of this type of loss, as well as noting some other examples of physical loss.

## TWO LANDMARK THEORIES OF GRIEF, TASKS AND PROCESS OF GRIEF, AND SPECIFIC REACTIONS TO LOSS

### Purpose

To develop an understanding of the theory of grief.

To identify some of the main symptoms of grief.

To identify and understand the basic task of grief and "grief work".

To provide a brief overview of the literature on grief and to use this to illustrate that although labels differ, the process is the same and can be considered within the three broad phases of Avoidance, Confrontation and Reestablishment.

To understand the assets and deficiencies of using "stage" theories.

### Instructions:

20 minutes — Develop a lecturette based on pages 18-24 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants.

The following material can be utilized in the preparation of the lecturette:

- Freud, 1917
- Lindemann, 1944
- Schulz, 1978
- Bowlby, 1961

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | ● Parkes, 1970<br>● Kavanaugh, 1972<br>● Kübler Ross, 1969 |
| | Stress how the process of grief is difficult because it resurrects old issues and the process of "de-cathecting" is so painful. Stress that the mourner does not have to forget the deceased (something which they will rightfully resist), but that a new and more healthy relationship must be established. |
| | PSYCHOLOGICAL MANIFESTATIONS OF GRIEF; PHYSIOLOGICAL MANIFESTATIONS OF GRIEF; AND SOCIAL MANIFESTATIONS OF GRIEF |
| | Purpose: |
| | To understand the components and reactions of grief in the three spheres: psychological, physiological and social. |
| | To understand that a number of typically abnormal feelings and experiences are quite normal in grief. |
| | Instructions: |
| 40 minutes | Develop a lecturette based on pages 24-28 of the participant manual. Present the lecturette, stopping frequently to solicit question/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | ● Lindemann, 1944<br>● Freud, 1917<br>● Parkes, 1970, 1972<br>● Schulz, 1978<br>● Siggins, 1966<br>● Jackson, 1957<br>● Bowlby, 1961 |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | - Kavanaugh, 1972 |
| | Stress again that the process of grief occurs after any type of loss, not solely loss through death. |
| | Ask the participants to see what similarities there are between the reactions discussed in the lecturette and those noted by themselves in Exercise II in which they listed their own responses to loss. Discuss. |
| | FORMS OF GRIEF REACTION |
| | Purpose: |
| | To identify the many forms in which the grief reaction may be seen. |
| | Instructions: |
| 15 minutes | Develop a lecturette based on pages 28-30 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following materials can be utilized in the preparation of the lecturette: |
| | - Averill, 1968<br>- Lindemann, 1944<br>- Parkes, 1965 |
| | Make sure to give enough examples for each of the forms of grief reaction to be differentiated. |
| | FACTORS INFLUENCING THE GRIEF REACTION: PSYCHOLOGICAL FACTORS, PHYSIOLOGICAL FACTORS, AND SOCIAL FACTORS |
| | Purpose: |
| | To identify and understand the variables influencing the individual's response to loss in the three spheres: psychological, physiological and social. |
| | To appreciate that there is no one response to loss and that what response there is will be determined by the unique situation and characteristics of the griever. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | To differentiate between "role-loss" and "object-loss". |
| | To understand the concept of anticipatory grief. |
| | Instructions: |
| 40 minutes | Develop a lecturette based on pages 30-36 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | Stress how crucially important it is to understand the meaning and implications of the loss from the individual perspective of the griever. Unless this is done, therapeutic attempts at intervention may be inappropriate. Make the point repeatedly that what constitutes a loss to one person may not constitute one to another and that the loss absolutely must be viewed from the unique perspective of the individual griever. |
| | --15 minute break-- |
| | ABNORMAL GRIEF |
| | (Includes sections on Social Factors Influencing Failure to Grieve and Abnormal Grief; Psychological Factors Influencing Failure to Grieve and Abnormal Grief; Symptoms and Behaviors of Unresolved Grief; and Mortality and Morbidity Following a Death.) |
| | Purpose: |
| | To identify the symptoms of unresolved or abnormal grief. |
| | To recognize that abnormal grief is a relative concept. |
| | To understand the social and psychological reasons for the failure to grieve appropriately. |
| | To appreciate the physical sequelae of grief after death. |
| | Instructions: |
| 40 minutes | Develop a lecturette based on pages 36-40 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | The following material can be utilized in the preparation of the lecturette: |
| | • Lazare, 1979<br>• Lindemann, 1944<br>• Siggins, 1966<br>• Jackson, 1957<br>• Parkes, 1965, 1964 |
| | HOW TO HELP THE GRIEVER |
| | Purpose: |
| | To identify what the griever must do in order to effectively confront and deal with grief. |
| | To identify and understand what is therapeutic in assisting the bereaved to deal appropriately with grief and what is not therapeutic. |
| | Instructions: |
| 20 minutes | Develop a lecturette based on pages 40-44 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| 10 minutes | Again referring to Exercise II, ask the participants what was helpful and not helpful to them when they sustained a loss. Discuss in light of lecturette information. |
| | DURATION AND RESOLUTION OF GRIEF |
| | Purpose: |
| | To provide an understanding that the grief process may only be evaluated in terms of the specific loss and the specific psychological, physiological and social factors which influence a particular grief reaction. |
| | To provide an understanding that it is a relative matter how long grief will last and that the bereavement |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | research is quite inconclusive about the duration of grief, but that usually it takes up to three years for most of the symptoms to resolve, although the more intense symptoms usually subside in six to twelve months. |
| | To provide an understanding that the saying "once bereaved, always bereaved" is true to an extent. |
| | To understand the nature of "anniversary reactions". |
| | To identify some criteria suggestive of a successful resolution of grief. |
| | Instructions: |
| 15 minutes | Develop a lecturette based on pages 44-45 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | • Lazare, 1979 |
| | • Kavanaugh, 1972 |
| | Stress how our culture has been unreasonable in expecting bereaved individuals to recover too soon. Admit that it is sometimes difficult to ascertain when symptoms have gone on for too long. Discuss the saying "once bereaved, always bereaved". |
| | WAKES, FUNERALS AND OTHER MOURNING RITUALS |
| | Purpose: |
| | To identify the three purposes of the funeral rite. |
| | To identify how the wake or Shivah facilitates some of the griever needs. |
| | Instructions: |
| 10 minutes | Develop a lecturette based on page 46 of the participant manual. Present the lecturette, stopping |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | frequently to solicit questions/comments from participants. |
| | Discuss with participants how the original functions of the funeral may have become perverted in our society due to the emphasis on money and show. Point out that in spite of this, the psychological functions of the funeral rites are still important for grievers. |
| | GRIEF AND CHILDREN |
| | Purpose: |
| | To understand how the myths and fairy tales told to children about death cause more harm than good. |
| | To understand how to inform a child most therapeutically of the death of a loved one. |
| | To understand why not allowing a child to participate in the events surrounding a death can cause many non-therapeutic effects. |
| | To understand how to evaluate the child's response to death and which responses to watch out for. |
| | To identify the rationale behind allowing children to be exposed to death as a natural part of life. |
| | Instructions: |
| 20 minutes | Develop a lecturette based on pages 47-50 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | • Grollman, 1974<br>• Fulton, 1967<br>• Kavanaugh, 1972 |
| | --15 minute break-- |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | SECTION C: THE DYING PATIENT<br>DEATH AS A CRISIS SITUATION<br>Purpose:<br>To clarify why the knowledge of impending death poses such a unique difficulty and why traditional coping mechanisms may be ineffective.<br>To explore the implications of being diagnosed as terminally ill.<br>To discuss the tasks of the dying person.<br>Instructions: |
| 15 minutes | Develop a lecturette based on pages 50-55 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
|  | Stress how the diagnosis confronts the individual with a problem that by definition is insolvable. Discuss how this prompts the need for new coping strategies (e.g., an altered time sense due to the lack of a long-term future) which may be initially anxiety-provoking in themselves because they represent a change from the norm.<br>The following material can be utilized in the preparation of the lecturette:<br>● Pattison, 1977<br>● Verwoerdt, 1966<br>● Koestenbaum, 1972<br>● Kalish, 1970 |
|  | TYPES OF DEATH<br>Purpose:<br>To help the participants understand that a terminally ill individual undergoes four types of death. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | To illustrate how Hospice can create a climate which can facilitate the ideal of having these four deaths occur as coincidentally as possible, or at least to minimize premature deaths in one of the four areas. |
| | Instructions: |
| 10 minutes | Develop a lecturette based on pages 55-56 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | Make sure to stress how Hospice is uniquely qualified to promote the appropriate convergence of the four types of death. |
| | THE ANTICIPATORY GRIEVING OF THE DYING PATIENT |
| | Purpose: |
| | To promote the understanding of the similarities and differences between the grief of the bereaved and the grief of the dying patient, i.e., the experience during terminal illness. |
| | To understand the emotional reactions of the dying patient and what would provide therapeutic intervention for them. |
| | To identify and understand the fears of the dying patient (also known as "part-aspects" of the experience of dying) and know how to work with them therapeutically. |
| | Instructions: |
| 20 minutes | Develop a lecturette based on pages 56-69 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | • Aldrich, 1974 |
| | • Pattison, 1966, 1977 |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • Verwoerdt, 1966 |
| 15 minutes | At the conclusion of the section in the lecturette on "Fears of Dying", direct each participant to complete Exercise III. Following this, the participants should return to the small groups and discuss their responses and reactions (or else have them remain in the large group, complete the exercise, and then process it fully). Check with the group to see if there is any relationship between the fears listed here and the personal feelings about death which are discussed in Exercise I. If so, discuss with them the reasons why this is the case. Try to help them see that one's fears about dying influence how they feel about death. One person from each group should summarize the group's experience to the rest of the group-at-large. Ask for any questions/comments on the exercise or the implications of it. |
| | DEFENSE MECHANISMS OF THE DYING PATIENT |
| | Purpose: |
| | To explore and understand the three groups of defense mechanisms used by dying patients to cope with the crisis of their terminality and the dying experience. |
| | To provide knowledge and understanding of therapeutic interventions to assist the patient in coping with the crisis of his/her own dying. |
| | To identify those variables which may influence the responses of the dying patient. |
| | Instructions: |
| 40 minutes | Develop a lecturette based on pages 69-80 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following materials can be utilized in the preparation of the lecturette: |
| | • Verwoerdt, 1966 |
| | • Weisman, 1972 |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Schoenberg and Senescu, 1970
- Pattison, 1977

Stress that defense mechanisms are not "bad" or unhealthy. Too many people think they are non-therapeutic. Point out how defense mechanisms assist an individual in coping when they are used appropriately. No one exists who does not use them. Discuss how it is the nurse's responsibility to support those defense mechanisms which are helping the patient cope. The participants must realize that in our society the words "defense mechanism" have come to imply an evasive, denying, or avoidance action which allows the individual to "run away." They must learn to appreciate that the defense mechanisms serve an adaptive function when used appropriately. They are crucial in allowing the patient to survive in the threat of his imminent demise. They do not imply weakness.

Provide the participants with numerous examples so that this information can "come alive" for them and not seem "cut-and-dried," as this type of information can tend to become too theoretical. Care must be taken to guard against this and to keep this lecturette viable and pertinent by focusing upon it as a way of understanding the dynamic issues the dying patient confronts.

--15 minute break--

## THE ISSUES OF ACCEPTANCE, WITHDRAWAL AND DETACHMENT AND HOPE

Purpose:

To facilitate an understanding of three major issues present throughout the dying process.

To identify the changes in emphasis with regard to these issues as the terminal illness progresses.

To identify and understand appropriate treatment interventions.

Instructions:

Develop a lecturette based on pages 81-83 of the

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 15 minutes | participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | Be sure to point out how the emphasis of these issues changes over time during the course of the terminal illness. Use this to stress how many variables change over the course of an illness and that the patient needs reassessment frequently. To respond to the patient later in the illness in the same manner in which he/she was responded to initially may be inappropriate given how the issues, and the patient, may have changed since then. Point out how this does not preclude some consistency in relating to the patient, e.g., one still needs to remain attentive, empathic and communicative but that it means the nurse must recognize that concerns and issues change over the course of a terminal illness and that therapeutic intervention will recognize this and provide for continual reassessment of where the patient is and what is needed. The nurse must avoid stereotyping patients in one role and continue to relate to them in one manner only, without appreciation for the fact that the circumstances and concerns of the patient change during the course of the illness, as do the patient's selves. |
| | THE CONCEPT OF "APPROPRIATE DEATH" |
| | Purpose: |
| | To introduce the notion of an "appropriate death." |
| | To identify those conditions which facilitate an appropriate death. |
| | To realize that what would constitute and "appropriate death" differs for each person. |
| | Instructions: |
| 5 minutes | Develop a lecturette based on pages 83-84 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from the participants. |
| | The following material can be utilized in the preparation of the lecturette: |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | - Weisman and Hackett, 1961<br>- Weisman, 1972 |
| 20 minutes | Note how an "appropriate death" will differ from person to person. Have the participants complete Exercise IV and consider what would constitute an appropriate death for themselves and what implications these have for their current lifestyles. Help participants to see that they should live their lives in ways which will preclude their having much "unfinished business" at the time of death. Discuss with the group what their thoughts are. (Note: the death need not be from a terminal illness. Note with the participants how many of them would choose to die from a terminal illness versus something else. Ask for their reactions. Discuss these in light of what implications they have for the individual's working with terminally ill patients.) |
| | THE NURSE-PATIENT RELATIONSHIP |
| | Purpose: |
| | To recognize and understand the unique role and function the nurse serves to the dying patient. |
| | To address the fact that working with dying patients can be anxiety-provoking at times and can prompt the nurse to seek distance from the patient who needs continued contact. |
| | To realize that the patient is the one who must set the tempo in becoming aware of and discussing the illness following initial diagnosis. |
| | Instructions: |
| 15 minutes | Develop a lecturette based on pages 86-87 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | - Verwoerdt, 1966, 1964 |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • Arteberry, 1967<br>• Schultz, 1978 |
| | Caution participants not to hide behind medical terminology or jargon when communicating with patients. This is an unhealthy avoidance mechanism since it allows us to pretend we are really relating to patients and giving them appropriate information that is understandable to them when in fact we are really distancing ourselves and not really making contact with the patients. |
| | HELPING THE DYING PATIENT |
| | Purpose: |
| | To identify the prerequisites for individuals working with the dying. |
| | To understand the communication skills necessary for working with the dying. |
| | To appreciate the importance of an assessment and a differential diagnosis of the fears of dying; as well as an overall evaluation and assessment of the patient's thoughts, feelings and concerns about death; the patient's prior experience with loss; and the patient's personal cultural/social value systems and pre-morbid characteristics. |
| | To identify the responsibilities of the nurse with regard to decision-making in the illness. |
| | To identify and understand the therapeutic interventions (Krant, 1977 and Pattison, 1966) which will promote "healthy dying" and an "appropriate death." |
| | Instructions: |
| 20 minutes | Develop a lecturette based on pages 87-91 if the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | • Verwoerdt, 1966 |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • Pattison, 1977, 1966<br>• Epstein, 1975 |
| | DEATH ACROSS THE LIFE CYCLE |
| | Purpose: |
| | To facilitate awareness and understanding that the issues of death must be understood in the context of that individual's life in general and the developmental tasks of that particular age specifically. |
| | To understand the identity tasks, conceptions of death and issues as a terminal patient for each of seven ages across the lifespan. |
| | Instructions: |
| 30 minutes | Develop a lecturette based upon pages 92-97 of the participant manual. Present the lecturette, stopping frequently to solicit questions/comments from participants. |
| | The following material can be utilized in the preparation of the lecturette: |
| | • Pattison, 1977<br>• Kastenbaum and Aisenberg, 1972<br>• Epstein, 1975<br>• Easson, 1970<br>• Erikson, 1950<br>• Gyulay, 1978 |
| | Stress again how dying patients must be responded to as unique individuals with diverse personal, social and cultural characteristics which influence their response. There is no one way to respond to dying patients. Persons must be considered individually and with respect to their unique characteristics and lifestyle. All dying patients are not alike. This is the danger in much of the popular literature on death and in the stage |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | theories: it does not pay enough attention to the individual variances of patients and this definitely must be done in order to have effective therapeutic intervention. |
| | CLOSING |
| | Purpose: |
| | To bring closure to the training session. |
| | To solicit evaluations and suggestions. |
| | Instructions: |
| 10 minutes | Make any final remarks desired |
| | Ask for evaluations, feedback and suggestions for future training sessions |
| | Adjourn |

# MODULE IV: FAMILY DYNAMICS AND FAMILY COUNSELING

FACILITATOR MANUAL

DEVELOPED BY:

William L. White, M.A.

# MODULE IV: FAMILY DYNAMICS AND FAMILY COUNSELING

## Purpose and Goals

The purpose of Module IV is to orient the hospice care nurse to family centered approaches to the care of hospice patients and their families. The goals of the module are to assist the hospice nurse in:

- Understanding the impact of death upon the family system
- Assessing the resources and vulnerabilities of families involved in hospice care, and
- Developing interventions aimed at supporting the dying patient and reducing the psychological vulnerability of the patient's family members

## Module Content

The module content includes the following areas:

- The rationale for family centered hospice care
- An overview of family systems theory
- The impact of adult death on the family system
- The impact of child death on the family system
- A Family Assessment model
- A review of potential nursing goals and nursing interventions with the families of hospice patients.

## Learning Objectives

At the conclusion of Module IV, participants will be able to:

- List four advantages of family centered hospice care
- Define and discuss the following concepts
    - family system
    - nuclear family, extended family, social network
    - the family life cycle
    - the enmeshed family/the disengaged family
    - open vs. closed family systems
    - family subsystems
    - family homeostasis
    - the identified patient/scapegoating
    - family roles

  - family rules
  - fusion vs. differentiation

- Describe the impact of death on the reorganization of roles within the family system

- List two functions of scapegoating in families with a dying member

- List two beliefs (that may lead to serious emotional disorders) often held by children who have been excluded from the family mourning process

- Describe the impact of child death on the parental subsystem, the marital subsystem

- Recognize the replacement child syndrome

- Identify the nine categories of information contained in the family assessment model outlined in the module

- Outline major nursing goals and nursing interventions for the families of dying patients.

## Perspective

There has been a tremendous amount of material condensed into the Family Dynamics and Family Counseling Module. This material represents an abstraction of major concepts on the family drawn from the fields of psychology and sociology and major concepts and current practices in family centered hospice care in the United States. The module has been designed to provide an introduction to a broad range of family issues important to caregivers in hospice programs. It is anticipated and encouraged that each instructor will develop areas of emphasis in the module based on their own expertise and the particular needs of the learning group.

The module has been organized into the following six submodules:

| | |
|---|---|
| Submodule A: | The first submodule overviews the total module, outlines the assumptions the module is based on, and identifies the advantages of family centered hospice care. |
| Submodule B: | The focus of the second submodule is on the understanding of the family as a dynamic system. This section provides the major terms and concepts that will later be used to understand the impact of death on the family system. The submodule contains a presentation of family types, family life cycles, and family system characteristics. |
| Submodule C: | This submodule examines the impact of adult death on the family system. Particular emphasis is placed on the role reorganization within the family that must occur due to the illness and subsequent death of an adult family member. |

Submodule D: This fourth submodule looks at the impact of child death on the family system. In particular, the impact of child death on the parental subsystem, the marital subsystem, and the sibling subsystem are examined.

Submodule E: The fifth submodule provides participants with a model of assessing the strengths and vulnerabilities of families involved in hospice care.

Submodule F: The final submodule outlines a series of nursing goals and nursing intervention that illustrate the provision of care to families involved in hospice programs.

The emphasis on the respective submodules can shift depending on the knowledge level of the participants. In groups that have a good working knowledge of family systems, greater emphasis and time should be devoted to submodules C through E. In groups that have significant hospice experience and/or training in death and dying but minimal training in family, greater attention and time should be devoted to submodule B. The relative balance between lecture, discussion, and structured learning experiences will vary according to the style of the instructor. In general, I would recommend that the greater the sophistication of the audience, the greater should be the emphasis on discussion and group experiences.

Module IV has been designed for a total of ten hours of instructional time. The approximate breakdown by submodule is as follows:

| | | |
|---|---|---|
| Introduction | | 1 hour |
| Submodule A: | Family Centered Care of the Dying | 15 minutes |
| Submodule B: | Understanding the Family As a System | 3 hours |
| Submodule C: | The Impact of Adult Death on the Family System | 2 hours |
| Submodule D: | The Impact of Child Death on the Family System | 1 hour |
| Submodule E: | Family Assessment | 1 hour |
| Submodule F: | Family Interventions | 2 hours |

Staff Requirements

One or two instructors are needed to present this module. The optimum group size is 20 with a maximum effective number of 30. Groups with more than 20 participants require two instructors. To effectively deliver the learning sequence outlined on the following pages, the instructors should ideally:

- Have an excellent working knowledge of family systems theory

- Have extensive knowledge of and clinical experience in grief work with families

- Have at least one or more years experience in group dynamics and task oriented instruction of health professionals

## Space Requirements

Space requirements for Module IV include one large meeting room and one small breakout area or room for each five to seven participants.

## Material Needs

The equipment and materials needed for Module IV include the following:

- Participant Manual for each participant
- Instructor's Manual for each instructor
- Name tags
- Prepared flip charts for each submodule (use of overhead projector and prepared transparencies can be substituted as per preference of the instructor.)
- Four flip chart pads
- One flip chart easel
- Markers
- Masking tape
- 35 millimeter movie projector (optional)
- Movie screen (optional)
- Movies noted in Instructional Activity Sequence (optional)

## Instructional Activity Sequence

The instructional activity sequence is displayed on the following pages. It should be emphasized that all times noted are approximations and are intended to serve as only general guideposts to manage the distribution of the submodules over the ten hours.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 7:30 - 8:00 | REGISTRATION<br>The instructor(s) should arrive early to greet participants as they arrive and to check for any last minute adjustments of the physical space (e.g., room temperature, arrangement of chairs, etc.).<br>WELCOME AND ADMINISTRATIVE DETAILS<br>Purpose<br>• To quickly complete administrative tasks needed to facilitate the delivery of the module<br>Instructions<br>Following introduction of instructor(s) and introductory remarks, cover the following:<br>• Expectation for active participation<br>• Break times<br>• Restroom locations<br>• Location of refreshments for breaks<br>• Eating places<br>NOTE: Review the above items only if information from previous modules is inapplicable due to new location or if module is presented as an independent workshop.<br>• Climate setting<br>- define space (large meeting room and break out areas)<br>- briefly introduce the variety of activities that will occur in Module IV |
| 8:15 - 9:00 | INTRODUCTORY EXERCISE<br>Purpose<br>• To establish the learning climate by involving |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | participants in a low-risk, self disclosing activity |
| | • To identify participants' expectations for the module |
| | • To identify participants' level of knowledge and experience in family work |
| 20 minutes | Instructions |
| Prepared flip charts | State that the module will begin with an exercise to clarify the participants' expectations and learning objectives for the module and their current level of knowledge and experience working with families. Utilize two flip charts labeled with the headings "Expectations" and "Knowledge and Experience". The latter chart should have the following three words listed underneath the heading: "Minimal, Moderate, and Extensive." |
| | Ask each participant to give one thing they hope to gain from the module and to state whether they would assess their knowledge and experience with family centered hospice care as minimal, moderate, or extensive. List each expectation on the first chart and place tally marks after each category on the second chart. |
| | (Use the completed tally sheets and learning objectives to ascertain the current knowledge level of participants and areas of desired emphasis in the module.) |
| 10 minutes | Review each learning objective on the first flip chart indicating whether that particular topic, skill area, or activity can be included in the module. |
| 15 minutes | Module Overview |
| | Instruct the participants to read the goals and learning objectives for Module IV found on pages 1-2 of the participant manual. Using the titles of the six submodules listed on a flip chart, review the organization of the module giving a short summary of each submodule and the amount of time that will be devoted to each. Present a brief |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | overview of the methodology of the module: lecturettes, discussions, structured learning experiences, etc. |
| 9:00 - 9:15 | Submodule A: Family Centered Care of the Dying<br>Purpose<br>• To introduce the module content and outline the major assumptions of the module<br>• To acquaint participants with the advantages of family centered hospice care<br>Instructions<br>Develop a short lecturette based on pages 2-4 of the participant manual. Review the module understandings and the advantages of family centered hospice care.<br>Discussion Questions: If we accept the family as the primary unit of hospice care, what implications does this have for the role of the nurse? |
| 9:15 - 10:00 | Submodule B: Understanding the Family as a System<br>Purpose<br>• To provide participants with an overview of some of the more basic family systems concepts and terms<br>• To assist participants in utilizing their own family experiences to understand the family as a dynamic system<br>Instructions<br>Develop a lecturette based on pages 2-7 of the Participant Manual. The approximate time allotted for each component, the content outline, and directions for the structured learning experiences follow. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 10 minutes | Review and discuss general system laws applied to families:<br>1. The family system as an entity is greater than the sum of its parts.<br>2. Anything which affects the family system as a whole affects each individual member of the family.<br>3. Any changes in one member of the family unit affects all other members individually and the system as a whole. |
| 5 minutes | Review the terms<br>• Nuclear family<br>• Family of origin<br>• Extended family<br>• Social network |
| 10 minutes | Instruct the participants to draw three concentric circles as in Figure IV-B and fill in the names of their nuclear family, extended family and social network. |
| 20 minutes | Develop and present a lecturette based on pages 7-11 of the Participant Manual. Review:<br>• The Family Life Cycle<br>• Changing nature of the family<br>• Ethnic, cultural and religious influences on family organization |
| 10:00 - 10:15 | Break |
| 20 minutes | Direct the participants to either count off or self select to make groups of 5-7 persons. Each member of the group is to briefly (3-5 minutes) describe the chart they completed earlier on the nuclear and extended family and social network and describe the current developmental stage of their nuclear family. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 15 minutes | Present a lecturette on family types based on pages 11-12 of the Participant Manual. Cover the following concepts.<br>● The enmeshed family<br>● The disengaged family<br>● The "normal" family<br>● The open family system<br>● The closed family system<br>The following materials can be utilized to help in preparation of the lecturette:<br>● Minuchin, 1967<br>● Satir, 1972<br>During the lecturette, direct participants to complete the exercises on pages 12-13 of the Participant Manual. Ask for a couple of volunteers to describe their examples for the enmeshed and disengaged families. |
| 30 minutes | Present a lecturette discussing the remaining concepts in Submodule B (pages 16-21 of the Participant Manual).<br>Include the following concepts.<br>● Family subsystems<br>● Family homeostasis<br>● Identified patient<br>● Family roles<br>● Family rules<br>● Fusion vs. differentiation |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Proceed through the concepts slowly soliciting examples and experiences from participants and answering all questions. Have the participants complete the exercise on family roles (p. 18) and family rules (p. 20) as you outline each of these concepts and solicit responses from participants. |
| 11:30 - 12:00 | Instruct the participants to return to the same small group that they met in earlier. Each participant is to select one of the following concepts. Share with the group how it applies to their own family of origin or nuclear family. Each participant should take about 3-5 minutes.<br>• Family types<br>• Family subsystems<br>• Family homeostasis<br>• Identified patient (Scapegoat)<br>• Family roles<br>• Family rules<br>• Fusion vs. differentiation<br>During each group exercise, the instructor(s) should float between the groups to provide any needed clarification of the instructions and to provide any necessary facilitation. |
| 11:55 | Bring the groups back together and note that after lunch we will be applying the concepts reviewed in the morning to understanding the impact of death on the family system. |
| 12:00 - 1:00 | Lunch |
| 1:00 - 2:45 | Submodule C: The Impact of Adult Death on the Family System<br>Purpose<br>• To provide participants with and understanding of the changes in the family system resulting from |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | the chronic illness and death of a family member<br>● To emphasize to participants the impact of death on the reorganization of roles within the family |
| | Instructions |
| 15 minutes | Review the concept of role reorganization as presented in pages 21-27 of the Participant Manual concluding with a summary of the B Family from the module. |
| 30 minutes | Direct participants to return to their groups. The task of each group is to complete the exercises on the B Family from pages 25-26 of the Participant Manual. Each group should select a recorder who will summarize the responses of the group. |
| 20 minutes | After participants return to the large group, each recorder should summarize the group's ideas on the role changes for each member of the B Family and the changes in each dyadic relationships in the family. |
| 40 minutes | Develop and present a lecturette based on pages 27-30 of the Participant Manual. Review and discuss the remaining concepts in Submodule C including:<br>● Redefinition of family rules<br>● Scapegoating<br>● Enmeshed and fused relationships<br>● Changing intimacy patterns<br>● Childrens' response to adult death<br>● Adult Death and the Social Network |
| 2:45 - 3:00 | Break |
| 3:00 - 4:00 | Submodule D: Impact of Child Death on the Family System |
| | Purpose |
| | ● To increase the participants' understanding of the changes in the marital subsystem, parental subsystem and sibling subsystem that occur |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | following the death of a child in the family |
| | ● To acquaint participants with the 'replacement child syndrome' |
| | Instructions |
| 30 minutes | Develop and present a lecturette based on pages 30-35 of the Participant Manual. Solicit the perceptions and experiences of the participants following the presentation of material on each of the subsystems. |
| 30 minutes | Direct participants to return to their small groups. The task of the group is to discuss special problems and approaches in providing hospice care to dying children and their families. The problems and approaches should be listed on flipchart paper by a group recorder and posted on the wall at the conclusion of the small group to share ideas between groups. |
| 4:00 - 5:00 | Submodule E: Family Assessment |
| | Purpose |
| | To increase participants skills in assessing the strengths and vulnerabilities of families involved in hospice care. |
| | Instructions |
| 15 minutes | Review and discuss the family assessment model outlined in pages 35-39 of the Participant Manual. Be sure and have participants critique the model and add any categories and questions they see as crucial in family assessment. |
| 30 minutes | Show a film such as "The Death of Ivan Illitch" or "A Time to Cry" from the series entitled "Begin with Goodbye." |
| 15 minutes | In the large group, have participants present their observations of the family using concepts from the module. The primary discussion question should be: What are the strengths and vulnerabilities of the family seen in the movie? |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 5:00 | Make closing comments noting that the final submodule will be completed between 8:00 and 10:00 A.M. the next morning.<br>Adjourn the group. |
| 8:00 - 10:15 | Submodule F: Family Interventions<br>Purpose<br>● To increase participants understanding of nursing goals and nursing interventions with families involved in hospice care<br>Instructions |
| 20 minutes | Review and discuss the nursing goals and interventions outlined in pages 39-47 of the Participant Manual. |
| 20 minutes | Direct the participants to return to their small groups. The task of the group is to develop additional nursing goals and nursing interventions based on their work with families in hospice programs. These should be written on flip chart paper and posted on the walls at the end of the groups as was done earlier. |
| 30 minutes | State that the closing group exercise for the module will apply knowledge gained from the module to various family situations encountered in the hospice program. Each group will address a different problem and then report out the major points of their discussion to the large group. Assign the topics/situations to the various groups or allow the groups to select one of the topics/situations.<br>Topic #1<br>Discuss how our understanding of families can be used to improve the care of patients who are admitted to the hospice program without a family? What particular problems do such patients experience? What can be done to address these problems? |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Topic #2 |
| | Discuss the following situation: Mr. C., who has been admitted to your hospice program, has a wife, two teenage children, and a long standing relationship with a mistress. Mrs. C. knows about the mistress, but does not know the relationship has continued to the present. Mr. C. wants to continue to see his mistress while in the hospice and feels the mistress could use the support of the program staff. How do we approach planning care for this "family?" |
| | What value dilemmas do you see the nurse confronting in this situation? How would you, for example, respond to: |
| | a. the husband's request that the mistress be allowed to stay overnight with the husband on the unit? |
| | b. the wife of Mr. C asking you if the mistress had visited or called Mr. C since his admission? |
| | Topic #3 |
| | Discuss the following situation: Mr. E. is a relatively young man whose family rejected him because of his homosexual lifestyle. Upon admission to the hospice program, Mr. E. wishes to maintain his involvement with his lover and reestablish contact with his family. How can this situation be approached to provide maximum support to Mr. E and those significantly involved with him? |
| | Topic #4 |
| | Select a patient/family situation that was particularly troublesome for you and your program to respond to. Try to utilize the concepts from the module and the experience of other group members to generate new approaches to the situation. |
| 1 hour | Bring the groups back together and allow each group 15 minutes to summarize their discussion to the larger group. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Module Summary |
| 10:15 | Summarize the major areas covered in the module and make any necessary closing comments. |

## FACILITATOR NOTES

## FACILITATOR NOTES

# MODULE V: MANAGING PERSONAL AND ORGANIZATIONAL STRESS IN THE CARE OF THE DYING

FACILITATOR MANUAL

DEVELOPED BY:

William L. White, M.A.

# MODULE V: MANAGING PERSONAL AND ORGANIZATIONAL STRESS IN THE CARE OF THE DYING

## Purpose and Goals

The purpose of Module V is to assist the hospice care nurse in the development of personal and organizational strategies to reduce the physical and emotional stress experienced in the care of the dying. The goals of the module are to assist participants to:

- Identify personal and organizational factors that contribute to the professional stress of the hospice care nurse
- Develop more effective strategies for stress management in the work environment
- Develop organizational and supervisory strategies to reduce the level of professional stress experienced by those caring for the dying

## Module Content

The Module content includes the following topic areas:

- Operational definitions of professional stress, stressor, stress response and professional burn-out
- Individual and organizational indicators of professional stress
- The impact of professional stress on family and interpersonal relationships
- The impact of grief (and accumulated grief) and mourning on the hospice care nurse
- Stress management techniques
- Balancing one's personal and professional lives
- Organizational conditions that increase professional stress
- How to structure the work environment to increase role supports and reduce role stressors
- Supervisory responses to reduce professional stress in team members (other nurses, volunteers, etc.)

## Learning Objectives

At the conclusion of Module V, participants will be able to:

- Describe the physiological and psychological symptoms of excessive stress
- Identify their own personal style of stress management and identify their own early warning signs of professional stress
- Describe at least three of the stress management techniques
- List at least three unique aspects of professional stress in the field of hospice care
- Diagram their own replenishment and support network
- Discuss three levels of incestuous organizational closure that significantly increase the level of stress experienced by organizational members
- Identify and define at least three role conditions that produce excessive stress in the hospice care nurse
- List and describe at least eight organizational strategies to reduce role stressors and increase role support for the hospice care nurse
- Describe effective supervisory responses to professional stress experienced by other members of the interdisciplinary team

## Perspective

The nature of professional stress is an important factor influencing the nature and quality of hospice care. Professional stress may have a profound effect on the physical, emotional and interpersonal health of the hospice caregiver. Excessive levels of professional stress can have a serious impact upon the effectiveness and vitality of the hospice organization. And professional stress can have a profound and detrimental effect on the quality of care provided to the dying patient and their family.

Module V is based on three premises. The first premise is that there are unique aspects to the problem of professional stress for nurses in the hospice care setting. These unique aspects, which are outlined in Module V of the Participant Manual, must be understood if we are to enhance the hospice care nurses' ability to manage professional stress. The second premise is that both individual and organizational factors must be examined if we are to understand the nature of professional stress within the hospice program. The third premise is that a comprehensive strategy to address professional stress must be capable of enhancing the stress management skills of the individual nurse, reducing role stress conditions, and increasing role supports within the interdisciplinary team.

The module has been organized into the following three submodules:

Submodule A: The focus of this first area is on the nature of professional stress, its impact and the personal strategies and techniques that can be developed to effectively manage it. Particular attention is given to stress experienced in the relationship between the nurse and the dying patient.

Submodule B: The focus in the second submodule is on those organizational processes and role conditions that excessively exacerbate the levels of professional stress experienced by the hospice care nurse. The submodule concludes with a review of organizational strategies to reduce professional stress.

Submodule C: The final area focuses on the supervisory role of the nurse in hospice programs and reviews effective supervisory responses to professional stress experienced by other members of the interdisciplinary team.

The emphasis on the respective submodules can shift depending on the particular participant group. For example, if a particular group contains a large number of nurses in supervisory positions within hospice programs, greater emphasis can be placed on submodules B and C. If the group is all student nurses with minimal experience in hospice programs or minimal experience in the care of the dying, greater emphasis should be placed on submodule A.

Module V has been designed for a total of eight hours of instruction time. The approximate breakdown by submodule is as follows:

| | |
|---|---|
| Submodule A: | 5 hours |
| Submodule B: | 2 hours |
| Submodule C: | 1 hour |

The tone of the module needs to be set early and needs to reflect an atmosphere that establishes the instructor's flexibility and willingness to bend the module structure to meet the needs of participants. Much of the module content focuses on the conflictual relationship between individual needs and organizational structures. Many of the problems experienced by participants in this conflictual relationship will be projected into the training process. Climate setting and instructor responses to issues raised by participants are thus critically important in modeling the content of the module. It is also important to clearly identify what can and cannot be accomplished within the parameters of the module. The module is designed as an overview and is not intended to represent an indepth presentation of stress theory nor an intensive skill building workshop.

## Staff Requirements

One or two instructors are needed to present this module. The optimum group size is 20 with a maximum effective number of 30. Groups with more than 20 participants require two instructors. Due to the nature of the material, instructors must ideally:

- Have a solid understanding of the nature of professional stress experienced by nurses, in general, and by the hospice care nurse, in particular
- Have a working knowledge of stress theory and stress management techniques
- Have a general knowledge of systems theory and role theory
- Have one or more years experience in group dynamics and task oriented instruction of health professionals

## Space Requirements

Space requirements for Module V include one large meeting room and one small breakout area or room for each five to seven participants.

## Material Needs

The equipment and materials needed for Module V include the following:

- Participant Manual for each participant
- Instructor's Manual for each instructor
- Name tags
- Prepared flip charts for each submodule (use of overhead projector and prepared transparencies can be substituted as per preference of the instructor.)
- Four flip chart pads
- One flip chart easel
- Markers
- Masking tape

## Instructional Activity Sequence

The instructional activity sequence is displayed on the following pages.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Note on Time Requirements:<br>Most instructors will find that module V could be easily expanded beyond the 8 hours in the current instructional design. The time allocations recommended on the following pages will always need to be adjusted based on the particular needs of the participants and the special interests and areas of special expertise of the instructors. The times displayed for the various activities represent merely the average time requirements we have experienced in their presentation.<br>It should be noted that groups with more than 20 participants require greater time for learning exercises and require shortening the time for lecture presentations. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 7:30 - 8:00 | REGISTRATION<br>The instructor(s) should arrive early to greet participants as they arrive and to check for any last minute adjustments of the physical space (e.g., room temperature, arrangement of chairs, etc.). |
| 8:00 - 8:15 | WELCOME AND ADMINISTRATIVE DETAILS<br>Purpose<br>• To quickly complete administrative tasks needed to facilitate the delivery of the module<br>Instructions<br>Following introduction of instructor and introductory remarks, cover the following:<br>• Expectation for active participation<br>• Break times<br>• Restroom locations<br>• Location of refreshments for breaks<br>• Eating places<br>NOTE: Review the above three items only if information from previous modules is inapplicable due to new location.<br>• Climate setting<br>- define space (large meeting room and break out areas)<br>- briefly introduce the variety of activities that will occur in Module V |
| 8:15 - 9:00 | INTRODUCTORY EXERCISE<br>Purpose<br>• To establish the learning climate by involving participants in a low-risk, self disclosing activity |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • To identify participant expectations for the module |
| | Instructions |
| 15 minutes<br>1 flip chart pad for each small group | State that the educational program will begin with an exercise to clarify the participant's expectations and learning objectives for the module. Instruct the group to count off or self select to make small groups of 5-7 participants. Direct each small group to introduce themselves, select a group recorder and prepare a list of expectations and learning objectives for the module. The lists are to be recorded on flip chart paper and reported out by the group recorder in the large group. |
| | NOTE: During each group exercise, the instructor(s) should float between the groups to provide any needed clarification of the instructions and to provide any necessary facilitation. |
| 15 minutes<br>Masking tape to attach group lists to wall | After participants return to the large group, each work group recorder summarizes the workshop expectations and learning objectives to the entire group. |
| 15 minutes | Course Overview |
| Prepared flip charts | When the group recorders have finished their summaries, review each of the learning objectives and report to the group whether each particular objective can be met in module V. Use these participant lists to identify those areas to place greatest emphasis on in the module. After this brief review, present the module goals and learning objectives. Where possible integrate the issues and concerns generated earlier by participants into the course overview. As mentioned earlier, the degree of emphasis on the three submodules should be based on the composition and needs of the particular participant group. Make explicit to the group the organization of the module, which sub-modules will be emphasized, and the approximate time that will be devoted to each sub-module. The times of specific activities listed on the following pages should be adjusted to reflect the group's desire for special areas of emphasis. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Areas of greatest interest by the particular participant groups can be emphasized by expanding the lecturette by time and depth, by increasing discussion time, and by adding exercises. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | SUBMODULE A: PERSONAL STRATEGIES TO MANAGE PROFESSIONAL STRESS |
| 9:00 - 9:45 | PRELIMINARY UNDERSTANDINGS<br>Purpose<br>• To provide participants with a common set of terms and definitions for the module<br>• To discuss aspects of professional stress unique to hospice care<br>• To acquaint participants with the physiological and psychological indicators of professional stress<br>Instructions |
| Prepared flip charts | Develop a lecturette based on pages 1-7 in the Participant Manual. The approximate time allotted for each lecturette component and the content outline is as follows: |
| 15 minutes | • Terms and Definitions<br>- stress<br>- stressor<br>- stress response<br>- professional stress<br>- professional burn-out<br>Solicit examples of each term from participants to make sure the distinctions between terms are understood. |
| 15 minutes | • Unique Aspects of Professional Stress in the Hospice Care Setting<br>- the nature of the patient<br>- the nature of successful care<br>- the redefinition of service roles<br>- greater responsibility in decision making<br>- the financial instability of many hospice programs<br>- the potential isolation of the home care nurse<br>- politics and personalities in the hospice field<br>Discussion Question: How would you compare your experience of stress in hospice care with nursing |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | care in other settings: If the participants do not have hospice experience yet, the discussion question is more appropriately: What stressful situations do you feel will be the most difficult for you to handle in the hospice program? Which potential situations are you most anxious about? |
| 15 minutes | ● Physiological and Psychological Indicators of Professional stress<br>- Health indicators<br>- Excessive behavior indicators<br>- Emotional adjustment indicators<br>- Relationship indicators<br>- Attitude indicators<br>- Value indicators<br>Discussion Questions: Which of the indicators in Exhibit V-A are most common among hospice care nurses? Are there other indicators you are aware of that are not included in Exhibit V-A?<br>Present the lecturette stopping after each component to discuss the material, solicit questions, and solicit additional ideas from participants.<br>The following materials can be utilized in the preparation of this lecturette:<br>● McLean, 1979<br>● Pelletier, 1977<br>● Seyle, 1974<br>● Seyle, 1956<br>● Vachon, 1978 |
| 9:45 - 10:00 | Break |
| 10:00 - 11:00 | FACTORS DETERMINING OUR RESPONSE TO PROFESSIONAL STRESS<br>Purpose<br>● To discuss, in detail, the roles of individual vulnerability, organizational context, and specific<br>● To explore with the participants those elements that determine one's vulnerability to professional stress |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | ● To orient the participants to the transitional stress involved in moving from traditional medical settings to the hospice environment<br>● To encourage participants to explore the role of anticipatory grief, grief, and accumulated grief in the professional stress experienced by the hospice care nurse |
| | Instructions |
| Prepared flip charts | Develop a lecturette based on pages 8-16 of the Participant Manual. The approximate time and content breakdown for each lecturette component is as follows: |
| 25 Minutes | ● Individual Vulnerability<br>- Genetic and developmental history<br>- Prior history of stress management<br>- Professional training<br>- Values and beliefs<br>- Death history<br>- Social and family supports<br>- Stage of life<br>- Life changes<br>- Motiviation of working with the Dying<br>Discussion Questions: Are there additional factors that we haven't covered that influence our vulnerability to stress? Which of the factors discussed do you feel are most important? |
| 5 minutes | ● Organizational Context<br>Review briefly:<br>- Stability of organization<br>- Emotional climate of organization<br>- Accessability of outside resources<br>- Peer relationships<br>- Supervisory supports<br>- Comfort of physical environment<br>Note that this area will be covered in depth in Section B of the Module. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | ● To assist each participant to identify their support and replenishment network<br>● To assist each participant in developing more effective personal strategies and techniques for managing professional stress |
| | Instructions |
| Prepared flip charts | Develop a lecturette based on pages 16-26 of the Participant Manual. Present the material in sequential order as outlined in the Participant Manual. There are a number of participant exercises interspersed within the lecturette. The overall sequence is as follows: |
| 5 minutes | ● Introductory remarks on personal strategies<br>The most important introductory point is that there is a wide diversity of stress management styles each of which may work well for particular individuals.<br>In reviewing styles and techniques of stress management, the key question for the participant is--Will this particular style or technique work for me?<br>It is also important to note or raise for discussion the problems nurses have focusing on their own needs given their socialization to always respond to the needs of others. |
| 30 minutes | ● Small Group Exercise<br>Direct the participants to return to the small groups they met in earlier in the day. The small group is to give each participant a chance to describe the most troublesome stressors they experience in their job and to describe their response to these stressors. This small group exercise is intended to be a time for sharing mutual problems and perspectives. After 25 minutes, direct the participants to turn to page 15 of the Participant Manual and complete the written exercise. After 5-10 minutes, bring the groups back together. The instructor should float among the groups during this exercise providing any necessary facilitation. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Note: If participants are students or potential volunteers not currently working in a hospice program, direct them to identify stressors they are currently experiencing in one of their roles, e.g., student, parent, spouse, etc. The key to the exercise is to simply get the participants to introspect and learn to identify their own unique stressors. |
| Prepared flip charts | Develop a lecturette based on pages 16-20 of the Participant Manual. The time and content components of the lecturette are as follows: |
| 25 minutes | • Begin reviewing the 12 general approaches to stress management<br>- Pace setting<br>- Limit setting<br>- Early warning signs<br>Direct each participant to complete the chart on pages 15-19 identifying their own early warning signs of professional stress<br>- Express thyself<br>- Physical replenishment<br>- Intellectual replenishment |
| 12:00 - 1:00 | Lunch |
| 1:00 - 2:00 | PERSONAL STRATEGIES TO MANAGE PROFESSIONAL STRESS (continued) |
| 15 minutes | Complete the review of general approaches to professional stress management outlined on pages 20-23 of the Participant Manual.<br>- Spiritual replenishment<br>- Boundaries between personal/professional lives<br>- Avoiding the Superperson Syndrome<br>- Alone time activities<br>- Time-out periods<br>- Learning to relax |
| 20 minutes | • Introduce the Replenishment Network Diagram and give the following sequential directions beginning at the top of the diagram moving counter-clockwise.<br>"List three people outside of your work setting that |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | provide professional support and encouragement for your work"<br>"List the three people inside your work setting that provide you the greatest level of professional support"<br>"List two people outside of your work setting that serve as mentors--teachers, professional guides, role models, etc."<br>"List three activities that you do by yourself that provide personal enjoyment and satisfaction"<br>"List three people (personal friends) with whom you regularly socialize that have no relationship to your work setting"<br>"List, in order of priority those persons within your family that provide the greatest level of personal support to you"<br>Discuss with the group their reactions to the completed diagram. Questions to be raised include: Which areas of the diagram were most difficult to complete? In which areas have you solicited support, but been denied? Which areas of support are most important for you? In what areas do you need to increase your supports? |
| 25 minutes | ● Review the stress management techniques on pages 25-26 of the Participant Manual.<br>- Medical treatment<br>- Individual, group, or marital counseling<br>- Career counseling<br>- Transcendental Meditation<br>- Benson's Technique<br>- Clinically Standardized Meditation<br>- Progressive Relaxation<br>- Biofeedback<br>- Aerobic exercise training<br>- Jogging<br>- Tension reduction exercises<br>- Assertiveness training<br>The following materials can be utilized in the prepara- |

TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE

tion of the lecturette:

- Harper, 1977
- Jones, 1962
- Michaels, 1971
- Pelletier, 1977
- Shubin, 1978

Depending on the knowledge and skill of the instructor, this overview of stress management techniques can be interspersed with one or two short demonstrations of such methods as progressive relaxation.

SUBMODULE B: ORGANIZATIONAL STRATEGIES TO MANAGE PROFESSIONAL STRESS

2:00 - 3:00 ORGANIZATIONAL PROCESSES AND ROLE CONDITIONS THAT CONTRIBUTE TO PROFESSIONAL STRESS

Purpose

- To explore with the participants organizational processes and role conditions that contribute to the professional stress of the hospice nurse

30 minutes Instructions

Prepared flip charts Develop a lecturette based on pages 27-33 of the participant module. Present the lecturette, stopping frequently to solicit questions and comments from participants.

Outline the following stages of organizational closure that increase the level of professional stress within a program.

- The organization of the program around a rigid ideology
- The director serving more as "high priest or priestess" than program manager
- The homogenization of staff (often recruited from within the existing social network of the staff group)
- Program isolation and reduced access to outside professional contact
- The extrusion of staff who challenge program ideology

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | - The projection of program problems on an outside enemy or scapegoating of individual staff<br>- Increased interpersonal conflict between staff<br>- Staff plots, conspiracies, uprisings<br>- The development of a work dominated social network by staff<br>- A shift of focus from the care of patients to the personal and interpersonal problems of staff<br>- The development of problematic social and sexual relationships between staff that disrupt team functioning<br>- A shift from direct communication to gossip and rumor<br>- A "loss of faith" in the ideology and a contagion of staff turn-over<br><br>Outline the ten role conditions described in Exhibit V-G , emphasizing Role/Person Mismatch, Role Conflict, and Role Connectedness.<br><br>Discussion Questions include: What are your experiences with the type of organizational closure described in the lecturette? What factors contribute to such closure and isolation? How do we prevent such closure? Which of the role conditions described are most prevalent in hospice care programs?<br><br>The following material can be utilized in the preparation of the lecturette:<br><br>● White, 1979A<br>● White, 1979B |
| 30 minutes<br><br>1 flip chart pad and marker for each small group | At the conclusion of the lecturette, direct the participants to return to their small groups. The task of each small group will be to generate a list of organizational conditions that they have experienced that increase professional stress. Each group should select a recorder to list on the flip charts the items generated by the group and select a reporter to present the group's findings. After 20 minutes of small group time, have the groups reassemble and report out to the large group. |
| 3:00 - 3:15 | Break |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 3:15 - 4:00 | ORGANIZATIONAL STRATEGIES FOR MANAGING PROFESSIONAL STRESS<br>Purpose<br>● To discuss with participants how the hospice care program can be structured to promote the health of the caregivers<br>Instructions |
| 20 minutes<br>Prepared flip charts | Develop a lecturette based on pages 33-36 of the Participant Manual. Present the lecturette, stopping frequently to solicit questions and comments from the participants.<br>- Hiring and Orientation within the Hospice Program<br>- Ongoing Supports within the Hospice Program<br>- Allowing the nurse guilt free exit from the program<br>The following materials can be utilized in the preparation of the lecturette:<br>● White, 1979 |
| 25 minutes | At the conclusion of the lecturette, direct the participants to return to their small groups. The task of each group is to generate a list of potential organizational strategies for managing professional stress in the care of the dying. A group recorder and reporter should be selected as was done earlier. After 15 minutes, instruct the groups to reassemble and have each reporter present the lists generated within the groups. |
| 4:00 - 4:45 | SUBMODULE C: SUPERVISORY RESPONSES TO VICTIMS OF PROFESSIONAL STRESS<br>Purpose<br>● To orient participants to supervisory responses to victims of professional stress within the hospice care program.<br>Instructions |
| 30 minutes | Develop and present a lecturette based on pages 36-42 of the Participant Manual. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| Prepared flip charts | Conclude Submodule C with a large group discussion. Discussion questions can include: How is the issue of professional stress currently handled by supervisors in your program? What sources of support exist for supervisors in your program? How do you balance the staffing needs of the program with the worker's need for time out periods?<br><br>The following materials can be utilized in the preparation of the lecturette:<br><br>● White, 1978 |
| 4:45 - 5:00 | CLOSING EXERCISE<br><br>Purpose<br><br>● To briefly summarize for the participants the major content areas and themes of Module V<br><br>Instructions<br><br>Briefly summarize the major learning areas of the workshop and provide any general closing remarks that you wish. |

## FACILITATOR NOTES

# MODULE VI: UNDERSTANDING OF THE PROCESS OF DYING AND THE DEATH EVENT ITSELF

FACILITATOR MANUAL

DEVELOPED BY:

Ida M. Martinson, R.N., Ph.D.

# MODULE VI: UNDERSTANDING OF THE PROCESS OF DYING AND THE DEATH EVENT ITSELF

## I. PURPOSE

The purpose of Module VI is to assist nurses in the understanding of the process of dying and the death event itself. The goals of the module are to assist trainees to:

- Identify and operationally define the major physiological mechanisms of dying
- Develop a basic understanding of the signs and symptoms which may be seen in the dying person
- Identify the death event
- List nursing measures appropriate to the presenting sign symptoms

## II. MODULE CONTENT

The module content includes the following areas:

- Historical review of the signs and symptoms of the dying process and death event
- Operational definition of dying and the death event
- Physiological indicators of dying and death on the cellular and system-wide level
- Impact of the breakdown in the cardiovascular system on physiological functioning, including the effect on the respiratory system
- Impact of brain and central nervous system involvement on physiological functioning
- Effect of bowel obstruction, constipation and incontinence
- Physiological results of hemorrhage, liver dysfunction, weight loss and anemia
- Process of starvation and dehydration
- Effects on the muscular system and other common signs and symptoms during dying
- Physiological changes following death

## III. LEARNING OBJECTIVES

As a result of successful completion of Module VI participants will be expected to demonstrate their ability to:

- Define physiological death and dying in the current multidisciplinary interpretation of death and dying
- Demonstrate an awareness of similarities and differences between cell death and somatic death, utilizing examples representing a terminal disease such as cancer
- Understand the important physiological interrelationships between failure of the heart, lungs, and brain, and the process of dying
- Describe specific physiological crisis events which most frequently occur during the dying process
- Explain the nurse's role immediately following a home death, in view of predictable physiological postmortem changes, as well as anticipated family support needs
- Evaluate the most important nursing measures concerning home care for terminal illness in view of predictable physiological aspects of the dying process, as well as appropriate symptomatic care

## IV. PERSPECTIVE

Module VI has been designed to orient nurses preparing to enter or currently working in hospice care programs to the process of dying and the death event. The module is designed as an overview and is not intended to represent an in-depth presentation of a course in physiology or fundamentals of nursing care.

The module has been organized into two submodules:

| | |
|---|---|
| Submodule A: | The focus of this first area is the historical definitions, current approaches, the physiological signs and symptoms of dying and death including the cellular level and selected organ symptoms including a brief introduction to the physiological changes following death. |
| Submodule B: | This submodule includes the signs and symptoms preceding death, a summary of the physiological changes and the appropriate nursing interventions preceding death, closing with suggested nursing support measures to family immediately post-death. |

Module VI has been designed for a total of six hours delivery time. The approximate breakdown by submodule is as follows:

Submodule A: 4 hours
Submodule B: 2 hours

The tone of the modules needs to be set early and reflects an atmosphere that establishes the instructor's flexibility and willingness to bend the module structure to meet the needs of participants. Much of the module content is difficult and not pleasant to think about; however, a serious atmosphere and high regard of the dying process and death event need to be maintained. Group discussions are necessary to help maintain a proper perspective and the module is recommended to be completed in one day, if at all possible.

## V. STAFF REQUIREMENTS

One instructor is needed to present this module. The optimal group size is 20 with the maximal effective number of 30. The instructor ideally should have:

- A functional working knowledge of physiology
- An extensive knowledge of body response to physiological crisis situations
- Some experience in nursing and in caring for dying patients
- One or more years of experience in the teaching of health professionals
- A medical-surgical nursing background--master prepared with strong basic science components or a nurse with a doctorate in physiology or a physician

## VI. SPACE REQUIREMENTS

Space requirements for Module VI include a large meeting room and one small break-out room for every 5-7 participants as well as a place to listen to sounds.

## VII. MATERIAL NEEDS

The equipment and materials needed for Module VI include the following:

- Participant manual for each participant
- Instructor's manual
- Name tags
- Prepared flip charts for each submodule. (Use of overhead projector and prepared transparencies can be substituted as per preference of the instructor)

- Four flip chart pads
- One flip chart easel
- Markers
- Masking tape
- Books on nursing management
- Tape recorder

## VIII. INSTRUCTIONAL ACTIVITY SEQUENCE

The instructional activity sequence is displayed on the following pages.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | REGISTRATION |
| | The instructor should arrive early to greet participants as they arrive and to check for any last minute adjustments of the physical space (e.g., room temperature, arrangement of chairs, etc.). |
| | WELCOME AND ADMINISTRATIVE DETAILS |
| | Purpose |
| 15 minutes | To quickly complete administrative tasks needed to facilitate the training event. |
| | Instructions |
| | Following introduction of the instructor and introductory remarks, cover the following: |
| | ● Expectation for active participation<br>● Break times<br>● Restroom location<br>● Location of refreshments for breaks<br>● Eating places |
| | NOTE: Cover the above three items if training for module is in different location than earlier modules. |
| | ● Climate setting<br>- define space (large meeting room and break-out areas)<br>- introduce briefly, the variety of activities that will occur in Module IV |
| | INTRODUCTORY EXERCISE |
| | Purpose |
| | To involve participants in the low risk, self-disclosing activity. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | To identify the group's current understanding of the physiology of dying. |
| | Instructions |
| 20 minutes | State that the module will begin with an exercise to identify participants' present understanding of the physiology of dying. Instruct the group to count off or self-select to make small groups of 5-7 participants. Each small group is directed to introduce themselves, select a group recorder and prepare a list of signs and symptoms of dying. The lists are to be recorded on flip chart paper and reported out by the group recorder. |
| | NOTE: During each group exercise, the instructor should circulate between the groups to provide any needed clarification of the instructions and to provide any necessary facilitation. |
| 15 minutes | Each work group recorder summarizes the signs and symptoms of the dying process generated from his/her group. |
| 10 minutes | Review the expectations and present the module goals and the learning objectives which have been prepared on flip charts. |
| 15 minutes | Develop a lecturette based on pages 5-9 of the participant manual. Present the lecturette on the historical definition and the current approaches to defining dying and the death event. Answer questions on this material before proceeding on to the cellular functioning, both normal and abnormal, found on pages 9-10 of the participant module.<br>The following materials can be utilized in the preparation of the lecturette:<br>• Morrison, 1971<br>• Carrington, 1921 |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • Inageki, 1974 |
| 45 minutes | Develop a lecturette based on pages 9-16 of the participant manual. Present the lecturette on the cardiovascular system, stopping frequently to solicit questions and comments from participants.<br>The following materials can be utilized in the preparation of the lecturette:<br>• Guyton, 5th Ed., 1976<br>• Mountcastle, 14th Ed., 1980<br>• Robbins and Cottran, 2nd Ed., 1980 |
| | Break |
| 20 minutes | Small group discussion |
| 45 minutes | Develop a lecturette based on pages 16-18 of the participant manual. Present the lecturette on the central nervous system, stopping frequently to solicit questions and comments from participants.<br>The following materials can be utilized in the preparation of the lecturette:<br>• Mountcastle, 14th Ed., 1980. Ruch and Patton, 20th Ed., Vol I (1979)<br>• Guyton, 5th Ed., 1976<br>• Darson & Segal, 19 , Vol IV |
| 20 minutes | Small group discussion. |
| 30 minutes | Develop a lecturette based on pages 19-20 of the participant manual. Present the lecturette on the respiratory system, stopping frequently to solicit questions and comments from participants.<br>The following materials can be utilized in the preparation of the lecturette:<br>• Robbins and Cottran, 2nd Ed., 1980 |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • Braunwald, In Harrison, 5th Ed. |
| 15 minutes | Small group discussion. |
| | Lunch Break |
| 15 minutes | Develop a lecturette on the physiological changes following death based on pages 20-21 of the participant manual. Present the materials, solicit questions and comments at the end of the presentation.<br>The following materials can be utilized in the preparation of the lecturette:<br>• Fisher,<br>• Evans, 1963<br>• Reading, |
| 45 minutes | Develop a lecturette on symptoms and symptomatic care based on pages 22-36 of the participant manual. Present the lecturette, stopping frequently to solicit questions and comments from participants.<br>The following materials can be utilized in the preparation of the lecturette:<br>• Doekel, 1976<br>• Keys, 1950<br>• Saunders, 1978<br>Hand out homework assignments of one or two symtpoms to each participant. Each participant has one hour of study time. When participants reconvene, make groups of five where five symptoms will be discussed. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 15 minutes | Develop a lecutrette based on page 36-39 of the participant manual. Present the lecturette, stopping frequently to solicit questions and comments from participants.<br>The following materials can be utilized in the preparation of the lecturette:<br>● (Home Care for Dying Children) by Ida Martinson - Bill Henry Hastings Center Report April 1980, pp. 5-7. Side issues involving social and legal aspects of death at home. Illustrative materials can be included which could be used in discussion of dying and death at home. |
| 15 minutes | Break into small groups for sharing of experiences using the brief case studies on the following page. |
| 5 minutes | Each group to give a five minute report of the discussion. |
| 15 minutes | Break into the same small groups and discuss the groups' developed lists of the signs and symptoms of dying - identifying the basic physiological process and system that leads to the specific sign and sumptom. |
| 10 minutes | Each group give a five minute report of the discussion |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| Case Study I | "Then at 4:00 in the morning, my phone rang. Because a friend was with Meredith, the parents had been sleeping in the other bedroom. But a change in Meredith's breathing had wakened them both and they found that her jaw was clenched and could not be opened. As we talked, she relaxed her jaw and was able to breathe through her mouth again. Though I offered to go over, they declined, saying that they would be able to manage now...<br>At 6:15 a.m. mother called again to say Meredith's breathing had changed significantly. "Can you come?" she asked. "My knees are shaking." I said I would be over immediately, but when I arrived at 6:30 Meredith had just died. Though heartbeat and breathing had both ceased, her body was still warm. She had died peacefully, had seemingly just stopped breathing. The father commented that these last two hours had passed by extremely fast. The mother pulled the pad up over Meredith's body and said, "Can't I keep her warm?" We stayed by the bedside quite awhile, then left and sat around the dining room table. |
| Case Study II | "We, as a family had a few crisis situations, but we were there the night he died. When I was awakened to give the pain medication that night, I noted the absence of restlessness; there seemed to be no need for pain medication. His feet were cool, evidence of circulatory failure, and his eyes, which had been glassy for the last day, were not glassy now. There may have been other signs, but these were enough. I awakened the family members who were sleeping and they were with him for the last five to ten minutes of his life." |

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# MODULE VII A: PHARMACOLOGY

## FACILITATOR MANUAL

DEVELOPED BY:

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# MODULE VII A: PHARMACOLOGY

## Purpose and Goals

The purpose of Module VII A is to introduce the hospice care nurse to the types of symptoms commonly seen in the terminally ill cancer patient for which drug therapy is appropriate and to describe appropriate pharmacological intervention.

The goals of the module are to assist participants to:

- Identify drug induced undesirable effects
- Have appropriate input into planning drug therapy
- Understand the types and dimensions of pain seen in patients with advanced, irreversible cancer
- Select and recommend appropriate drug therapy and to suggest other therapeutic modalities for nausea, constipation, diarrhea, anorexia and other symptoms common in terminal disease
- Appreciate the need for high quality physical and psychosocial care for successful symptom management

## Module Content

The module content includes the following topic areas:

- Common symptoms in terminal disease
- Definitions of pain
- Dimensions of severe, chronic pain
- Presentation of severe, chronic pain
- Modalities of managing pain
- Affect and pain
- Analgesic agents
- Analgesic dosing
- Myths about narcotic analgesics
- Communications about symptoms and the disease process and pain
- Nausea and vomiting

- Diarrhea
- Constipation
- Iatrogenic symptoms
- Adjunctive steroid therapy
- Marijuana and LSD
- Life style and symptom control

Learning Objectives

At the conclusion of Module VII A, participants will be able to:

- List six common symptoms associated with advanced cancer and indicate which may have an iatrogenic component
- Define the major differences between acute and chronic pain
- Describe the aching to agony continuum of chronic pain
- List three dimensions of chronic pain
- Describe the presenting symptoms of severe, chronic pain
- Describe the reasons for selecting a relatively high narcotic dose in severe, chronic pain
- List equipotent doses and comparable durations of action of morphine, methadone and meperidine
- Describe the problem of drug accumulation associated with methadone dosed every 4 hours
- Describe the rationale for regularly scheduled narcotic doses rather than prn dosing in severe, chronic pain of a physical origin
- Define endorphins
- Describe the rationale of adjunctive phenothiazines in severe, chronic pain
- Describe two reasons why tricyclic antidepressants should not be routinely used in reactive depression associated with chronic pain
- List five etiologies of nausea in cancer patients

- List three reasons why piperazine side chain phenothiazines are the favored group in nausea associated with narcotics
- List the five major classes of cathartics and one advantage and disadvantage of each class
- List five symptoms for which steroids may be helpful in advanced cancer patients
- Describe the original rationale of adding cocaine to narcotic cocktails and the results of a double-blind study which mediates against the use of cocaine in this manner
- List three possible causes of diarrhea and constipation in advanced cancer patients
- Describe two potential advantages and disadvantages of using marijuana as an adjunctive drug in chemotherapy

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 30 minutes | Registration |
| 15 minutes | Welcome and Administrative Details |
| 20 minutes | Pretest<br>**Purpose:**<br>• To allow trainees to determine their entry level knowledge bases<br>• To provide focus on some of the major considerations to be developed in the module |
| 15 minutes | Common Symptoms in Terminal Disease<br>The trainer should ask trainees to name as many common symptoms associated with advanced irreversible cancer as the group can identify. |
| 15 minutes | The trainees should then be asked to indicate any drugs which are commonly used for disease or symptom management in advanced cancer and which might precipitate or exacerbate any of the symptoms which the group has identified. |

Common Symptoms in Terminal Disease

The following symptoms were identified as being amenable to drug therapy and/or being exacerbated by drug therapy in an interdisciplinary, longitudinal study of advanced cancer patients that was conducted in 1970-71.[1]

| Symptom | Drugs which may exacerbate the symptoms |
|---|---|
| pain | |
| nausea and vomiting | chemotherapy, narcotics |
| anorexia | narcotics |
| diarrhea | chemotherapy |
| constipation | narcotics, anticholinergics |
| dysphagia | anticholinergics |
| stomatitis | anti-infectives |
| dyspnea | |
| cough | |
| anxiety | |
| confusion | narcotics, CNS depressants |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

| | |
|---|---|
| depression | narcotics, CNS depressants |
| insomnia | |
| incontinence | laxatives |

Many of the drugs intended to alleviate symptoms may cause or exacerbate other symptoms. The patient must be viewed as a whole, not as a host of multiple symptoms to be managed individually.

Pain

Classical definition: a more or less localized sensation or discomfort, distress or agony resulting from the stimulation of specialized nerve endings.[2]

This definition is inadequate for description and differentiation of pain associated with cancer.

Pain Therapy

Gate Control Theory[3]
Endorphine Theory[4]

Read enclosed article on pathophysiology of pain, Hayner (1978).

Phases of Pain

Three phases of pain:

Immediate, acute, chronic

Read enclosed commentary on phases of pain, deJong (1979)[1]

Acute Pain

Can be described as occurring on a continuum:

MILD → MODERATE → SEVERE

Mild acute pain is commonly managed well with aspirin or acetaminophen.

Moderate acute pain is commonly managed well with aspirin plus codeine if aspirin alone is insufficient.

severe acute pain commonly requires high dose narcotic analgesics, often by parenteral routes

acute pain can usually be rationalized by the patient and care giver as:

- a short-lived experience to be borne stoically
- an important diagnostic or monitoring parameter
- an experience that will lessen, then disappear

Chronic Pain

Chronic pain, conversely may present only a dull, background ache on one day, excruciating agony on the next and revert to the ache on the third day. The pattern of aching to agony presents more as a circular than a straight line continuum.

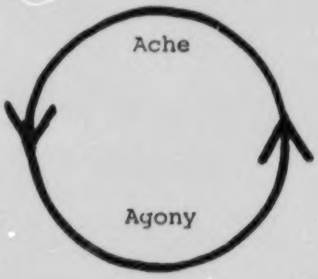


Figure 1

Incidence of Pain

Acute pain occurs intermittently in 50-75% of patients with cancer.

Chronic aching pain may occur in half to three-quarters of patients with advanced cancer.

Chronic agonizing pain occurs in only 20-40% of patients[1,5] with advanced cancer. When it does occur, it is devastating both physically and psychologically.

Immediate and acute pain are managed quite readily with conventional medical measures.

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

Chronic pain management requires a recognition of and attention to, the following:

- The pain serves no purpose and must be reduced to a level with which the patient can function physically and interact socially
- few patients can rationalize chronic pain since it is not associated with a healing process

Dimensions of Severe, Chronic Pain

Pain usually presents initially as a physical phenomenon.

Causes:

- Tumor growth resulting in pressure in nerve endings
- pressure in sensitve organs
- impaired local or regional blood flow
- bone involvement
- organ degeneration

With time, a psychological dimension appears (commonly in days to weeks).

The physiological dimensions are commonly seen as:

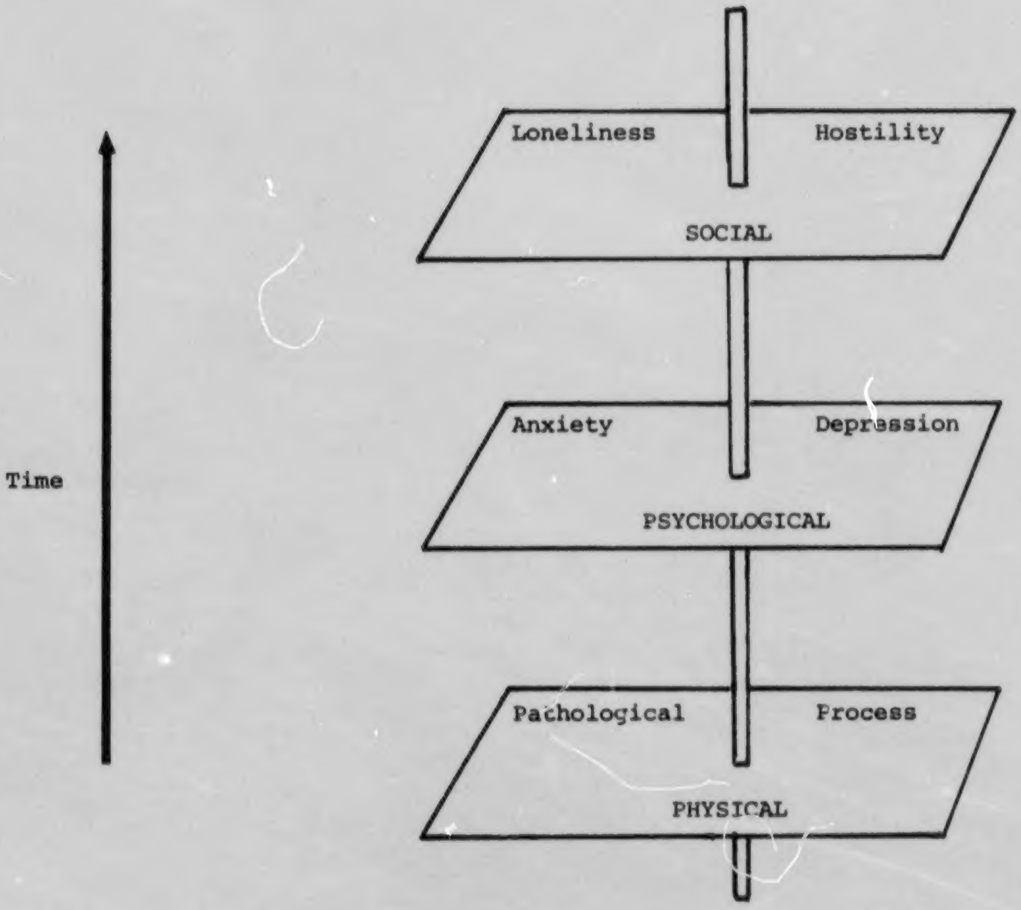
- anxiety
- reactive depression
- insomnia

With additional time (commonly weeks to months after the initiation of the physical dimension) a social dimension may further complicate the picture.

The patient becomes increasingly hostile and lonely (people tend to avoid hostile patients).

FIGURE 2

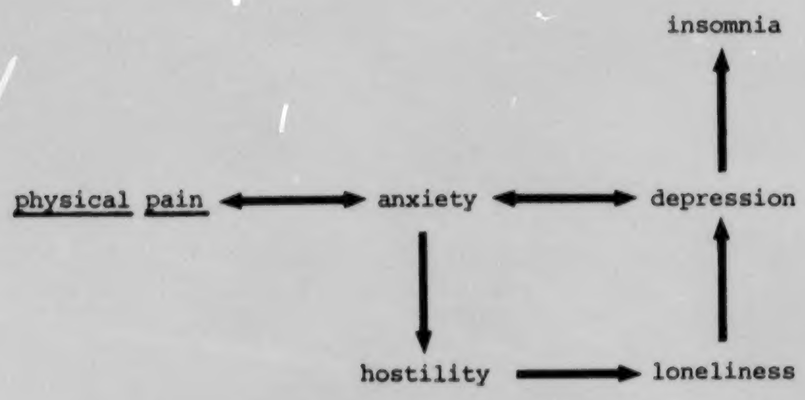
DIMENSIONS OF SEVERE, CHRONIC PAIN


Loneliness
Hostility
SOCIAL
Anxiety
Depression
PSYCHOLOGICAL
Time
Pachological
Process
PHYSICAL

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Presentation of Severe, Chronic Pain<br><br>Physical pain, anxiety and depression appear to be closely related and are usually most effectively treated as an interconnected series of symptoms rather than separately.<br><br>Similar changes in the central nervous system levels of biochemical transmitters (e.g., serotonin, norepinephrine) may occur with pain and with affective changes, especially anxiety.<br><br>Anxiety exacerbates perception of physical pain and physical pain begets anxiety.<br><br>The affective changes appear to present more as a mixed anxiety-reactive depression syndrome than as two separate affective disorders.<br><br>Anxiety often results in hostility and hostility frequently produces loneliness which exacerbates reactive depression. Insomnia, or less commonly hypersomnia, is common with depression.<br><br>The symptom complex of patients in severe, chronic pain frequently presents in a manner shown in Figure 3.<br><br>Attempts to manage any one of the symptoms without attention to the interrelationships between the various symptoms will usually not succeed.<br><br>For example:<br><br>• Drug treatment of depression may help to alleviate insomnia and may lessen anxiety somewhat, but it would not reduce the other symptoms greatly<br><br>• Drug treatment of the insomnia would be of little help for the other symptoms<br><br>• Drug treatment of the physical pain alone would not alleviate the other symptoms<br><br>The critical point on the pain-symptom-complex diagram for therapeutic intervention is between pain and anxiety. Frequently, concurrent intervention for pain and anxiety results in alleviation of the full symptom complex. |

FIGURE 3

THE PRESENTATION OF SEVERE, CHRONIC PAIN


insomnia
physical pain
anxiety
depression
hostility
loneliness

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

Pharmacological Intervention

Pharmacological intervention in pain control can be effective in managing the physical component and can be of some adjunctive value in the affective component. It is of little value in alleviating social distress.

A drug therapy approach to severe, chronic pain (agony) may be characterized as follows:

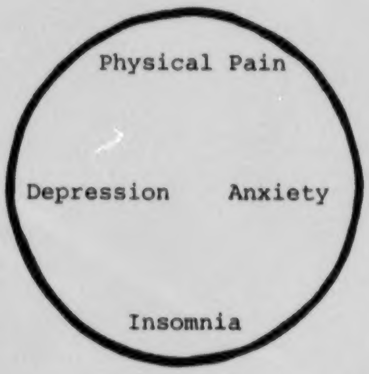

Physical Pain
Depression
Anxiety
Insomnia

Figure 4

Purely symptomatic drug management has been suggested as follows:

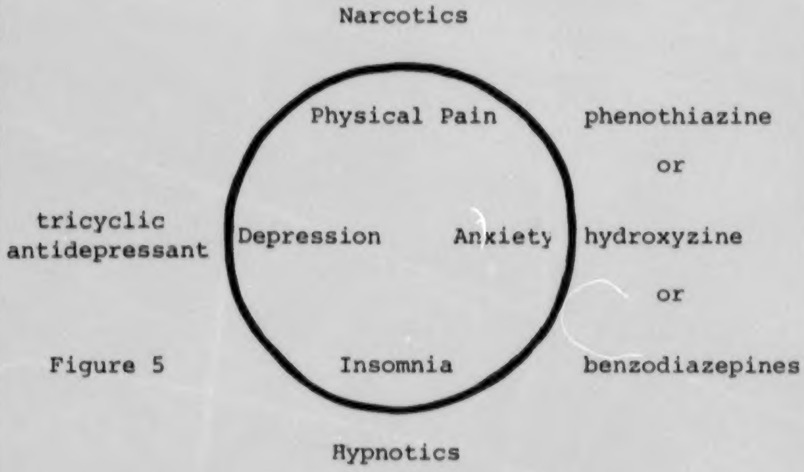

Narcotics
Physical Pain
phenothiazine
or
tricyclic
antidepressant
Depression
Anxiety
hydroxyzine
or
Insomnia
benzodiazepines
Hypnotics

Figure 5

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

This polypharmacy approach may include as many adverse effects as benefits. A more appropriate approach for most patients is:

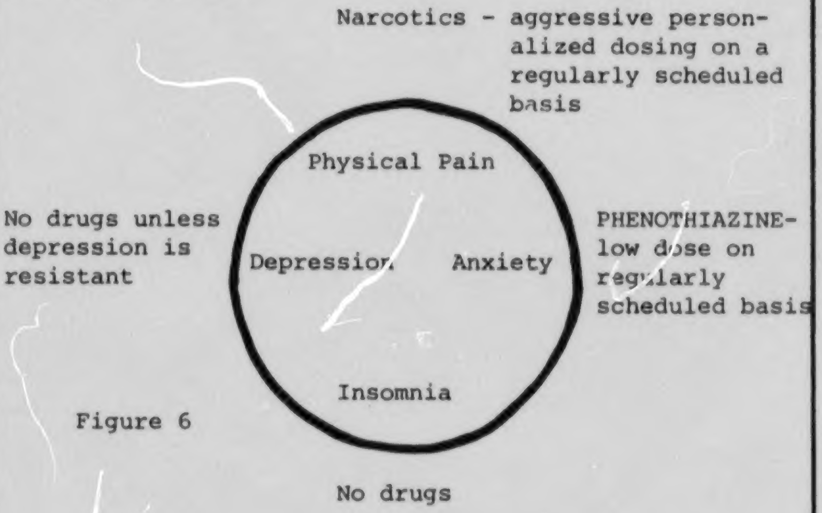

Narcotics - aggressive personalized dosing on a regularly scheduled basis
Physical Pain
No drugs unless depression is resistant
Depression
Anxiety
PHENOTHIAZINE- low dose on regularly scheduled basis
Insomnia
No drugs

Figure 6

**Rationale**

**Physical Pain**

When physical pain is severe, the potent narcotic analgesics are normally the drugs of first choice. When patients have severe pain, it is inappropriate to attempt to alleviate the pain with less potent analgesics (e.g., aspirin, propoxphene) and to then progress to narcotics if the less potent drug is not effective.

Rather, the most potent drug should be used initially and then a less potent agent might be used subsequently once initial pain control is achieved.

**Anxiety**

Anxiolytic drugs alone are of limited usefulness. The cause of the patient's anxiety must be identified and addressed in most cases if adequate pain control is to be achieved.

One major cause of anxiety in patients who have severe chronic pain is the continual recurrence of the pain. Such recurrences are inevitable if the patients take

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

their analgesics on a "prn" basis, i.e., in response to the recurrence of pain. As mentioned earlier, pain and anxiety cause similar biochemical shifts in central nervous system transmittors. When pain recurs after a dose of analgesic loses its effect, the patient commonly becomes anxious about the recurrence of the pain. The anxiety produces biochemical shifts which are similar to those that occur with physical pain. Thus, the anxiety appears to exacerbate the physical dimension of pain through a biochemical mechanism. Therefore, the prevention of recurrence of pain is achieved more easily and usually with lower doses of analgesics than is the treatment of pain after it has recurred. Prevention of recurrence is accomplished by administering the next dose of analgesic before the previous dose has lost its effect.

Over a decade ago, Dr. Cicely Saunders, the founder and medical director of St. Christopher's Hospice in South London stated about severe, chronic pain:

> Such pain calls for continuous control, and drugs must be given regularly. Pain itself is the strongest antagonist to analgesia, and it should be kept in constant remission. If treatment anticipates pain, the patient will not anticipate pain and will not continually increase it by fear and tension.[7]

Many other factors may induce anxiety. Patients' concerns about family, finances and disease often lead the list. Two of the most common causes of anxiety are fear of pain and of loneliness. It is therefore important that patients be continually reassured that pain can be controlled and that they will not be deserted or left alone by caregivers and loved ones.

Anxiety due to external causes often exacerbates the patients' pain. In 1971, while serving as a visiting clinical pharmacist at St. Christopher's Hospice in London, I met Mrs. E., a 60-year-old lady with metastatic carcinoma of the breast who did not respond to drug therapy for her continuous pain despite high doses of narcotic, chlorpromazine and amytriptyline. It was only after the patient's fifth day in the Hospice that her sister told us that Mrs. E. expressed great fear that her suppurative breast lesion would spread and involve her face. She had requested that her sister help her to kill herself if this occurred. The staff was then able to reassure Mrs. E. that this greatly feared spread would not occur. Only then, when her anxieties were allayed, did the patient respond to treatment of her pain.[8]

Anxiolytic drugs can be useful adjuncts to administering the analgesics on a regularly scheduled basis and to identifying and addressing other sources of patients' anxiety.

Three classes of adjunctive antianxiety agents have been reported to be useful. Phenothiazines are potent antischizophrenic agents (tranquillizers). The high doses used in schizophrenia are unnecessary and inappropriate due to the risk of adverse effects. Low dose phenothiazines are effective antianxiety drugs. Phenothiazines have been reported to be additive to narcotics in producing analgesia. This claim is probably invalid, but slightly lower doses of narcotics in combination with phenothiazines may be as effective as slightly higher doses of the narcotics used alone. Phenothiazines are anxiolytic in low doses. Higher doses have anti-schizophrenic activity. The low doses employed as narcotic adjuncts in severe, chronic pain do not have antipsychotic activity. Nor do they produce the large number of dose related antichlolinergic side effects seen with anti-schizophrenic doses. Furthermore, the low dose phenothiazine adjunctive therapy is seldom implicated in the tardkive dyskinesias and dystonias that are associated with long-term, high-dose phenothiazine treatment.

The principal advantage of phenothiazine adjuncts in severe, chronic pain is the antiemetic activity of the drugs. Narcotic analgesics commonly cause nausea. In some patients, nausea and vomiting may be chronic and violent. Commonly, the nausea is subtle. Patients are sometimes not aware that they are nauseated. They just report feeling "awful". Questioning about their specific symptoms often discloses reports of feelings of unease in the stomach.

Of the three classes of adjunctive, antianxiety agents that are commonly used with narcotic analgesics, phenothiazines are clearly the most effective antiemetics.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Prevention of nausea usually requires less aggressive drug therapy than does treatment of vomiting. Low dose phenothiazines, e.g., prochlorperazine 5 mg two to three times daily, is an effective drug which is utilized in several hospice programs as an adjunct to narcotics.[6] Hydroxyzine has also been used successfully (personal communication, R. Twycross, April 18, 1980) and diazepam is currently being considered as a potentially useful antianxiety adjunct in several centers. A phenothiazine is the drug of choice when the patient reports nausea.<br>The relative potencies and actions of various phenothiazines will be discussed under management of nausea and vomiting.<br>Hydroxyzine (Atarax, Vistaril, others) is available in oral solid, oral liquid and parenteral dosage forms. It is an antihistamine with central nervous system depressant, anticholinergic, antiemetic, antispasmodic and local anesthetic effects. Some claims of mild analgesic activity have been made, but this analgesia is of little value in severe, chronic pain. Anticholinergic side effects, especially dry mouth, are common. These effects are dose related and they are additive with the effects of other anticholinergic drugs which the patient may be receiving. Parenteral administration is discouraged due to marked pain at the site of intramuscular injection. Intraveneous injection is contraindicated due to toxicity. There is no rectal dosage form. Drowsiness and dizziness are frequently associated with hydroxyzine. These effects are also dose related and are additive with the effects of other sedating drugs. The useful dose of oral hydroxyzine as either the hydrochloride or the pamoate salt for use as an adjunct to narcotic analgesics is normally 10 to 15 mg three times a day.<br>There are currently seven benzodiazepines commercially available in the United States. One of these drugs is used primarily as an anticonvulsant and one as a hypnotic. The remaining five are promoted primarily as antianxiety agents. These drugs are: |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

| Generic Name | Proprietary Name |
|---|---|
| chlordiazepoxide | Librium, others |
| diazepam | Valium |
| oxazepam | Serax |
| chlorazepate | Azene, Tranxene |
| prazepam | Centrax, Vestran |

In patients with impaired metabolic function, all of the benzodiazepines may have prolonged activity with unwanted sedation, with the possible exceptions of oxazepam and lorazepam. Diazepam is generally shorter acting than chlordiazepoxide and the former drug is therefore preferred to the latter. Oxazepam and lorazepam may be the most appropriate benzodiazepines for this use because these drugs are excreted unchanged, i.e., do not require liver metabolizing.

The benzodiazepines are sedating and are not antiemetic. They do not appear to offer any advantage over phenothiazines or hydroxyzine.

The most important therapeutic intervention for the lessening of patients' anxiety is not anxiolytic drugs. The causes of the anxiety must be identified and addressed. It is important that the patient be given every possible opportunity to express his or her anxieties. This requires careful, skillful listening on the parts of all care givers, including family and friends. Some patients are unable to express their anxieties to their physicians or family members, but will do so to a nurse or other person who they do not know as well. Failure to identify a patient's source of anxiety may be the most common reason for seemingly appropriate pain management to fail.

## Depression

Depression is very commonly seen in patients with advanced irreversible disease. Commonly, tricyclic antidepressant drugs are prescribed for these patients. Usually, this is inappropriate.

The depression seen in most terminal patients is reactive or exogenous. Reactive depression does not usually respond well to antidepressant drug therapy. Reactive depression is common throughout life and as the

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | patient becomes more accustomed to his or her disease and physical, social, economic and spiritual needs are addressed, the depression usually lessens.<br>The reactive depression that is commonly seen in cancer patients presents as a mixed anxiety-depression. When the patient's anxiety lessens, the depression usually lessens as well. The tricyclic antidepressants produce anticholinergic side effects which can be very troublesome to the patient and which are additive with the side effects of other drugs with anticholinergic activity that are commonly used in symptom management.<br>Endogenous depression can occur in cancer patients just as it can in any patient. This disease should be treated aggressively, usually with tricyclic antidepressant drugs. Depressed patients often appear very angry. They may express extreme anger about their disease, their caregivers and the "unfairness of it all". It is improbable that a seriously depressed patient will be able to accept his/her disease and make the necessary psychological adjustments. Therefore, drug therapy of serious depression in advanced cancer patients should be considered. Tricyclic antidepressant therapy is effective in about 75% of the patients with endogenous depression.<br>Cancer patients who have histories of previous episodes of endogenous depression or familial histories of "melancholia" are at greater risk of becoming severely depressed. The differentiation of reactive and endogenous depression is difficult and a skilled psychologically trained clinician may be helpful in managing severe depression. When the patient's depression becomes a dominant factor in his/her personality, management of the depression with antidepressant drugs may be indicated and may be very helpful. These are potent drugs with significant side effects and they should be used by a clinician experienced with them. Full therapeutic doses should be employed, but it is often necessary to start with a low dose and slowly titrate upward to an effective dose. This is particularly true in physically debilitated patients who tend to experience more severe and frequent side effects than patients who are otherwise healthy. |

The anger, hostility and constant bemoaning of one's fate that are seen with severe depression make such patients difficult to be with. Skilled social support of these patients is necessary and avoidance of them by caregivers frequently exacerbates their psychological difficulties. Realization that the patient may have endogenous depression, a disease that requires management, and is not attacking the caregivers personally due to an aberrant personality, helps many nurses to interact more appropriately with such patients.

Antidepressant drug therapy takes a minimum of 10 to 14 days to become effective. With slow upward titration of the dose, the optimal effect may not be seen for several weeks. Patients may appear to respond rapidly due to the sedative effects of the drugs permitting sleep. Insomnia is a common and troublesome accompaniment of depression. Patients should be encouraged to continue to take their antidepressant drug even though a rapid effect may not be seen. Nurses should also remember that severely depressed patients seldom attempt suicide. Suicide more commonly is attempted when the depression resolves somewhat. If the patient plateaus in the resolution of the depression, there may be an increased suicide risk as presented diagramatically in Figure 7.

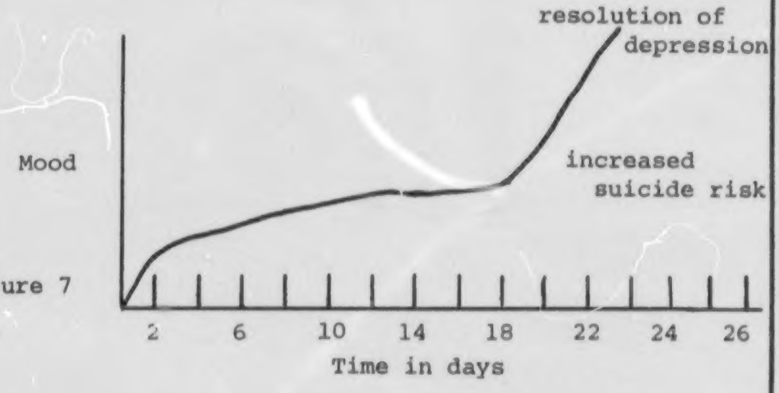


Figure 7

Observation and monitoring of severely depressed patients is recommended.

## Modalities of Pain Management

There are many effective modalities that are employed in managing the pain associated with advanced irreversible disease. Analgesic drugs are the most common and often the most effective modality. Seldom, however, is only one modality indicated.

Analgesic drug therapy is described in detail in other sections of this module. Analgesic drugs are particularly useful in disseminated pain. When pain can be localized, more specific therapy may be a useful adjunct or alternative to systemic analgesics.

## Nerve Blocks

When the pain can be localized to a specific area, especially in soft tissue, reversible (local anasthetic) or irreversible (necrolytic) nerve blocks may be indicated.

Article by Bonica[9,2]

Gerbasshagen has described cancer pain that is amenable to nerve blocks as being characterized by symptomatology of so-called carcinomatous or sarcomatous neuritis.[10] This is very similar in signs and symptoms to sympathetic reflex dystrophy. The signs and symptoms include:

- pain
- hyperpathia
  - hyperthesia
  - hyperalgesia
- neurovascular instability
  - vasoconstriction
  - vasodilation
- sudomotor disturbances
  - hypohidrosis
  - hypohidrosil
  - anhidrosis
- piolomotor changes

Such pain often occurs in 6 to 12 months following radical and effective surgery in which tumor is removed.

Blocks with local anesthetics usually have to be repeated every few days. Such reversible blocks should

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

always be used diagnostically before neurolytic blocks are employed. In many patients, neurolytic blocks have to be repeated periodically. Complications that are associated with neurolytic blocks include:

- Bladder paresis
- Bowel paresis
- Muscle paresis
- Headache
- Paresthesia
- Numbness

Irradiation

Spot irradiation is a valuable pain relieving modality[11] for well localized pain, especially in bony metastases.

Radiation therapy of pain appears to produce pain relief through

- Decrease or removal of pressue in nervous structures
- Reduction of heteroplastic infiltration under the area of radiation
- Disappearance of ulceration and pressure in hollow organs
- Resolution of inflammatory reaction

Radiation therapy has been useful in the following types of cancer pain:

- Head and neck pain involving the trigeminal nerve, paranasal cavities, pharynx and thyroid
- Peripheral pulmonary tumor, breast cancer involving metastases, lymph nodes and ulceration
- Pancreatic carcinomas, endopelvic metastases and biliary tract carcinoma
- Endopelvic tumors in the female genital system
- Testicular and prostatic tumor
- Renal tumor sites following surgery and bladder pain
- Headache due to cerebral metastases and intracranial lesions
- Radicular pain due to bony mestastases of the spine
- Subperiostial pain due to bony metastases

Surgery

Surgery is obviously a primary treatment for many cancers.

Hypophasectomy is a well known procedure for relief of pain in certain tumors and a variety of neurosurgical procedures have been developed for pain due to cancer.

In less than 70 years, about 15 different neurosurgical operations have been devised to treat intractable pain.[12] Frequently, neurosurgical procedures for pain do not produce as good results as their proponents claim. The potential sequelae of such procedures must be carefully considered.

Palliative surgery may be useful for pain relief when tumor growth causes pain due to pressure or obstruction. Palliative surgery may be particularly useful for pain due to tissue anoxia due to vascular insufficiency.

### Behavior Modification

Patients' response to pain is largely a result of their socialization and learned behaviors. Modification of behavior may be particularly useful in relieving pain which is due to or exacerbated by tension or a learned response. Biofeedback has been employed successfully by psychologists as has hypnosis.

Such modalities are often appropriate only when the patient has a reasonably long life expectancy.

### Psychosocial Approaches

Psychosocial support is an essential component of effective management of pain. Good drug therapy without effective psychosocial support often is unsuccessful. A discussion of psychosocial support is outside of the scope of this module. However, consideration of this modality should not be divorced from consideration of drugs in symptom control.

### Transcutaneous Electrical Nerve Stimulation (TENS)

TENS is a treatment modality that has been very useful in radicular pain of the spine and is being advocated in a variety of arthralgias. Its usefulness in cancer pain is limited, but due to the relative safety and low cost, TENS is sometimes considered in cancer pain.

Article by Ventafridda et al[14,3]

## Trigger Point Injections

Trigger points are small circumscribed tissue areas that are highly irritable. Injection of local anesthetics into trigger points for relief of pain in associated areas is common practice in many pain clinics. The resulting pain relief often lasts for longer than the duration of the anesthetic. Injection of saline or probing of the trigger point with a hypodermic needle alone may produce similar results.

Trigger point injection may be a useful modality in treating muscle pain of cancer patients, particularly in pain secondary to surgery or tissue injury.

Wyant article[15,4]

## Palliative Chemotherapy

Pain due to cancer has been attributed to three major causes.[13]

- Compression and/or infiltration of nerve structures by the neoplastic process
- Inflammatory processes around or within a tumor
- Action of chemical mediators

Antineoplastic drugs, hormones and glucocorticosteroids may be useful in lessening pain through reduced tumor load, antiinflammatory activity and relief of tumor induced pressure or obstruction when there is not a realistic chance of total elimination of tumor. Locally administered antineoplastic drugs, e.g., via ligated arteries, may be particularly useful in such cases.

## Analgesic Drugs

Analgesics are commonly described as mild, moderate or potent just as acute pain is commonly described as mild, moderate or severe. This classification of analgesic potency is of limited value in treating chronic pain.

Effective management of the chronic pain frequently seen in terminal patients usually requires agressive initial treatment with narcotic analgesics. Once

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | initial pain relief is obtained, maintenance may require continuing narcotics or may require only aspirin.<br>Analgesic drugs may be conveniently classified as non-narcotic and narcotic. Non-narcotic drugs include salicylates - most notable aspirin, acetaminophen and a variety of other agents, most of which require a prescription. None of these agents is more effective than aspirin alone as demonstrated by Moertel et al.<br>Moertel et al. paper [5]<br>Commonly, analgesics are administered in combinations rather than as single entities. Moertel's group therefore conducted a similar study on combination analgesics.<br>Moertel et al. paper[5] |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Proposyphene is a prescription analgesic which the FDA reclassified as a narcotic in 1980. Proposyphene is a very popular, but not especially efficacious drug as described in a review by Miller et al.<br><br>Miller et al. paper[6]<br><br>The popularity of proposyphene does demonstrate that patients' perception of analgesic efficacy is an important factor in the therapeutic usefulness of pain relieving medications. When patients' perceptions of what their pain medication should do are not appropriate, patient education should be undertaken. Positive understanding and expectations about drugs are important.<br><br>The agonist-antagoinst group of prescription analgesics includes pentazocine (Talwin) and nalbuphine (Nubain). These drugs produce potent analgesia following parenteral administration. The clinical usefulness of the oral dosage forms is less consistent and predictable. These drugs do not appear to have any advantages over narcotics in severe, chronic pain associated with terminal disease. Additionally, the agonist-antagonist analgesics are associated with adverse psychological reactions including hallucinations in elderly patients. The theoretical advantage of agonist-antagonists is that they may have a lower incidence of dependence indication than the narcotics. Dependence is not a problem in appropriately dosed narcotic analgesic therapy of patients with severe, chronic pain, however, as discussed in a later section of this module, the agonist-antagonist drugs are relatively expensive and can produce drug dependence.<br><br>Most analgesics have mechanisms of action that are either centrally or peripherally mediated. Narcotics act centrally, apparently by occupying a variety of stereospecific receptor sites. The drugs appear more to decrease central perception or effect of pain than to lessen the pain at its source. Salicylates and the majority of other non-narcotic analgesics appear to act peripherally at the source of the pain stimulus. These drugs act by inhibiting the formation of the enzyme(s) responsible for the synthesis or activity of certain prostaglandins. These prostaglandins are mediators of pain and inflammation. |

Because narcotics and nonnarcotic analgesic-anti-inflammatory drugs have different mechanisms of action it is often useful to use a drug from each group concurrently. This is especially useful when there is an inflammatory component to the pain as in rapid tumor growth and bony metastases.

Aspirin is a drug of choice when patients can tolerate it. Aspirin is associated with a high incidence of gastrointestinal side effects in patients with severe underyling disease. Therefore, aspirin is not well tolerated by many patients with advanced disease. Additionally, aspirin is contraindicated for concurrent use with several antineoplastic agents and in patients with clotting disorders. Acetaminophen (Tylenol, others) is not as useful as aspirin because acetaminophen does not have clinically useful antiinflammatory activity. Detailed pharmacological information on aspirin and acetaminophen is available in standard pharmacology references. The new, nonsteroidal anti-inflammatory drugs which have been introduced primarily as antiarthritic medications are often the best alternatives to aspirin. The drugs also are effective analgesics although only one of them (ibuprofen) has FDA approval for that indication. A discussion of the comparative activities of the nonsteroidal antiinflammatory drugs follows.

The New Non-Steroidal Anti-Inflammatory Drugs

Four non-steroidal anti-inflammatory agents were introduced in the United States between 1974 and 1976 for the symptomatic treatment of rheumatoid arthritis. Three of these drugs are propionic acid derivatives (ibuprofen, naproxen, and fenoprofen). A fourth (tolmetin) is structurally related to indomethacin. Ketoprofen, a phenylalkanoic acid derivative, is currently available in the U.S. only on an investigational basis. Sulindac (Clinoril) was introduced in 1978. This drug is similar to indomethacin in its activity.

Anecdotal claims of great safety and efficacy for these drugs have been made, but controlled scientific studies usually have demonstrated no greater efficacy for these drugs than for aspirin taken in appropriate doses. While these drugs are significantly more expensive than aspirin, they offer little advantage over aspirin except in patients in whom aspirin is contraindicated.

Many patients claim an initial greater effect of the new drugs over aspirin due to the psychological aspects of a new drug. Clinicians might expect frequent patient requests for the new drugs due to the progressive symptomatic nature of the diseases for which the drugs are indicated.

Low doses of ibuprofen produce only an analgesic effect, higher doses are required for anti-inflammatory activity. All of the drugs appear to be as effective as aspirin with respect to anti-inflammatory activity. Naproxen (250 mg BID) has been reported to be equivalent to 3-6 gm of aspirin per day. Tolmetin (1,200-1,500 mg/day) ketoprofen (200-300 mg/day) and ibuprofen (1.6-3.2 gm/day) are reported to be equivalent to 3-5 gm of aspirin per day.

Both aspirin and the new, non-steroidal anti-inflammatory drugs suppress the synthesis of prostaglandins. This is the proposed mechanism of anti-inflammatory activity.

Naproxen has a 12-15 hour half-life which allows for twice a day dosing. The others require 3-4 doses per day; other pharmacokinetic properties of the drugs are similar. All of the drugs are highly serum protein bound and may displace other protein bound drugs including hydantoins, sulfonylureas, and sulfonamides.

The greatest incidence of adverse effects affect the GI tract. Heartburn, nausea, vomiting, and abdominal pain are the most frequently reported GI side effects. Gastrointestinal bleeding has also been reported to occur with these drugs. Other effects reported include headache, dizziness, light-headedness, pruritis, skin rashes, tinnitis, and some sodium and fluid retention which could produce edema.

Symptomatic improvement may occur within a few days to a week but the manufacturers of each of these drugs advise that improvement may not be seen with less than two weeks of therapy.

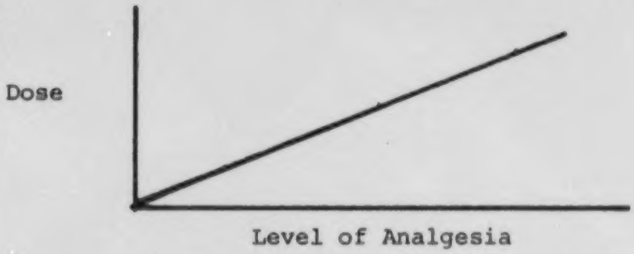
Individual patients who have not responded to one of the new agents have responded to another. A pattern or reason for these interpatient differences has not been described.

A tabular comparison of aspirin and the new nonsteroidal anti-inflammatory agents is presented on the attached sheets.

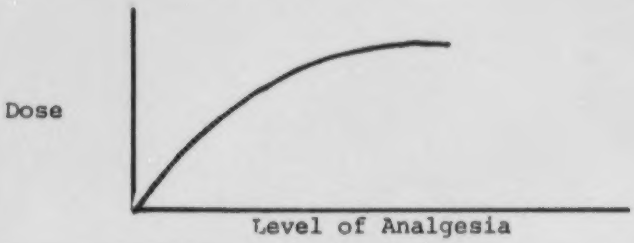
Narcotic Analgesics

The narcotic analgesics include natural and synthetic analgues of morphine. With the exception of propoxyphene (discussed above), codeine and its congener oxycodone (in Percodan, Percocet, Tylox), all of the narcotic analgesics produce similar effects when they are administered in equianalgesic doses at appropriate time intervals.

Codeine and oxycodone are effective analgesics in moderate to severe pain. With increasing doses, these drugs appear to produce less increased analgesia. While the dose-response curve for the other narcotics might be characterized as follows,



the dose response curve for codeine and oxycodone may present in this manner.



## NON STEROIDAL ANTIINFLAMMATORY AGENTS

| | Ibuprofen<br>Motrin®<br>(Upjohn) | Naproxen<br>Naprosyn®<br>(Syntex) | Fenoprofen<br>Nalfon®<br>(Lilly) | Tolmetin<br>Tolectin®<br>(McNeil) | Sulindac<br>Clinoril®<br>(Merck, Sharp&Dohme) | Aspirin<br>(Various) |
|---|---|---|---|---|---|---|
| Oral absorption | readily | 100% | 80% | 90% | 90% | variable* |
| Peak blood levels (hours) | 1 | 2-4 | 2 | 0.5-1 | 2-3 | 0.66 fasting;<br>1.66-2 normal meal |
| Plasma T-1/2 (hours) | 2<br>(1.6-2.5) | 13<br>(12-15) | 3 | 1 | 7 | aspirin 20 min; salicylic acid: 3-6 |
| Metabolism | liver | liver | liver | liver | liver | liver |
| Excretion | 1% free, complete in 24 hours | 10% free, 95% eliminated in 5 days | 5% free, 90% in 24 hours | 10% free, 90-95% in 24 hours | 2.7 free, 66% in 24 hours | 10% free as salicylic acid |
| Protein binding | 99% | 99% | 99% | 99% | 93%<br>metabolites 95-98% | aspirin very slight;<br>salicylic acid: 50-80% |
| Therapeutic levels (mcg/ml) | ? | 23-49 | ? | ? | 0.1-0.2mg% | 20-30** |
| Indications: | | | | | | |
| Rheumatoid arthritis | yes | yes | yes | yes | yes | yes |
| Osteoarthritis | yes | yes | yes | yes | yes | yes |
| Ankylosing spondylitis | no | yes | no | yes | yes | yes |
| mild to moderate pain | yes | no | no | no | no | no |
| Dosage range (mg/day) | 1200-2400 | 500-750 | 2400-3200 | 600-1800 | 200-400 mg | 4500-7500 |

|  | Ibuprofen | Naproxen | Fenoprofen | Tolmetin | Sulindac | Aspirin |
|---|---|---|---|---|---|---|
| Dosage forms | 300 mg white tabs, 400 mg orange tabs 600 mg tabs | 250 mg yellow scored tablets | 300 mg yellow and ocher and 600 mg pulvules | 200 mg white tabs imprinted with "200" and "McNeil" | 150, 200 mg tablets | 325 mg tabs, and suppositories |
| Approximate cost at suggested dose for 1 month | $18.50-22.00 | $ 14.00-19.50 | $ 23.50-29.00 | $22.50-30.00 | $ 18.50-23.50 | Bayer: $5.75-10.00 |
| Contraindications | hypersensitivity & allergy to aspirin | hypersensitivity & allergy to aspirin | hypersensitivity & allergy to aspirin | hypersensitivity & allergy to aspirin | hypersensitivity & allergy to aspirin | oral anticoagulant therapy |
| Relative Contraindications | pregnancy, impaired liver function | pregnancy, nursing, oral anticoagulants, impaired renal function, CHF, bleeding disorders | upper GI disease, impaired renal function | upper GI disease, bleeding disorders, CHF, nursing, pregnancy | upper GI disease, CHF pregnancy nursing | pregnancy, bleeding disorders, impaired renal function |
| Adverse reactions: GI tract | diarrhea,GI upset(4-15.9%), bleeding,ulcers nausea(3-9%) heartburn (3-9%) | abdominal pain, GI upset, diarrhea, cholestatic jaundice | dyspepsia, constipation, abdominal pain, anorexia, blood in stool | GI upset (16%), abdominal pain, heartburn (2%), ulceration, constipation (1.6%), nausea (4%) | GI upset, constipation transient LPT elevation | GI upset, abdominal pain, ulceration, anorexia, hepatomegaly with chronic use |
| Skin | rash, 3-9% pruritis | rash, pruritis | rash,pruritis (10%), urticaria, sweating | rash (3%) pruritis (2%) | rash pruritis | pustular acneform eruptions after continued use |
| CNS | headache, dizziness (3-9%), light-headedness, depression, fatigue | headache, drowsiness, dizziness, light-headedness, vertigo | tremor, dizziness, drowsiness(14%), confusion, insomnia headache (14%) | dizziness (4%), light-headedness (4%), drowsiness(2%), nervousness(2%) headache (7%) | dizziness headache nervousness vertigo | headache, dizziness, mental confusion, |

|  | Ibuprofen | Naproxen | Fenoprofen | Tolmetin | Sulindac | Aspirin |
|---|---|---|---|---|---|---|
| Adverse Sensory Effects | blurred vision(<1%) colored vision(<1%), tinnitis(<3%) | visual & hearing upset | tinnitis(10%), blurred vision, hearing loss | tinnitis(2.5%) | tinnitis | tinnitis hearing loss |
| Cardiovascular System | fluid retention |  | palpitations (4%) | mild edema (2.5%) | mild edema |  |
| Lab test interference | abnormal LFT's, WBC counts, BUN elevation | abnormal LFT's | anemia, abnormal LFT's BUN elevation | slight decrease in hematocrit, hemoglobin without GI bleeding, granulocytopenia | elevated alkaline phosphotase | may alter urine glucose determinations with glucose oxidase reagent (Tes-tape) and cupric sulfate reagent (Clinitest) |
| Miscellaneous | decreases platelet aggregation; increases bleeding time |  |  |  |  |  |
| Placental crossing | ? | yes | ? | ? |  | yes |
| Appearance in milk | ? | yes | ? | ? |  | yes |

* Oral absorption of aspirin dependent upon stomach contents and stomach emptying time.

** Therapeutic levels of aspirin attained after oral doses of 4 G/day or more

TIME/MATERIALS

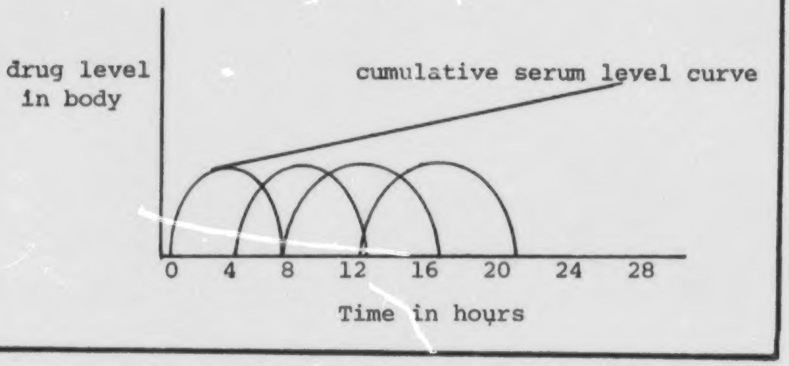
INSTRUCTIONAL ACTIVITIES OUTLINE

Thus, when patients require rapidly increasing doses of codeine or oxycodone to obtain or maintain pain relief, consideration of another drug might be in order. The risk of dependence induction secondary to patients taking extraordinarily high doses of codeine or oxycodone in unsuccessful attempts to obtain pain relief is probably higher than if the patients were to take any of the other narcotic analgesics. It is therefore adviseable to discuss with patients their doses of such drugs as Percodan, and, if rapidly increasing doses or decreasing time intervals between doses are needed, alternative narcotic analgesics might be considered.

The following table lists relative doses and durations of action for equivalent analgesia with several commercially available narcotic analgesics. These data are based upon clinical experience in chronic pain associated with terminal cancer and on published literature. Many published studies on equianalgesic doses suggest different relative doses. Some of these data are based on acute pain models or single dose studies, however, and are not therefore fully applicable to severe, chronic pain associated with terminal disease.

The longer acting narcotic analgesics, notably methadone and levorphanol may accumulate in the body if the drugs are administered at too frequent intervals. These two drugs normally should not be administered more often than every six hours. If the drugs are administered at more frequent intervals, the levels in the body gradually increase as demonstrated in the following dose response curve:

Cumulative Dose Response Curve for Narcotic Administered Too Frequently



## NARCOTIC ANALGESICS

## APPROXIMATE EQUIANALGESIC DOSES

| Drug | Route | Dose | Average Duration of Action |
|---|---|---|---|
| Alphaprodine (Nisentil) | SC | 20-60 mg | 2-3 |
| Hydromorphone (Dilaudid) | PO | 2-4 mg | 4 |
| | PR | 3-6 mg | 4 |
| | IM, SC | 3-4 mg | 4 |
| Levorphanol (LevoDromoran) | PO | 2-3 mg | 6-8 |
| | SC | 2 mg | 6-8 |
| Meperidine (Demerol) | PO | 100-150 mg | 2.5-3.5 |
| | IM, SC | 75-100 mg | 2.5-3.5 |
| Methadone (Dolophine) | PO | 10 mg | 6-8 |
| | IM, SC | 7.5-10 mg | 6-8 |
| Morphine Sulfate | PO | 15 mg | 4-6 |
| | IM, SC | 10 mg | 4-6 |
| Oxymorphone (Numorphan) | PR | 2.5 mg | 4 |
| | IM | 1-1.5 mg | 4 |

Because the drug tends to depot in fatty tissue, patients receiving doses every four hours may appear to be doing well, but after several days or weeks of therapy, may become obtunded. This is due to the depot sites become saturated with a result of an excessive amount of free drug in the body. This problem may be more common in elderly patients than in younger subjects.[16]

When the objective of narcotic treatment is to prevent the recurrence of pain, it is obvious that drugs with a duration of at least six and preferably eight hours are preferable to shorter acting agents. It is obvious from the table of approximate equianalgesic doses that alphaprodine is not a drug of choice for this use. Meperidine is also a short acting drug which is commonly administered in doses that are insufficient for optimal pain relief. The frequency of meperidine being underdosed was described well by Marks and Sachar.[17]

Marks and Sachar paper[7]

Patients sometimes have biases against narcotics which have not provided pain relief previously or preferance for drugs which have worked for them. Utilizing drugs in which patients have confidence is useful. If a patient doubts the efficacy of a drug, it should generally be avoided. Conversely, if a patient believes that a particular narcotc analgesic is highly efficacious, the use of that drug is advised even if the health professionals caring for the patient might prefer a different drug due to duration or experience.

When patients are unable to take oral narcotic analgesics due to nausea or dysphagia, rectal suppositories should be considered. Rectal dosage forms are absorbed from the superior rectal veins. The anatomical configuration and physiological function of that area is variable, especially in patients who have disease involvement in the lower gastrointestinal tract. Therefore, large interpatient variations in response to rectal drugs must be expected and patients must be titrated to response as with oral drugs. Both oxymorphone and hydromorphone are available as suppositories. Opium and belladonna (B + O) suppositories are also commercially available in the United States. That dosage form should be avoided, however, due to the large amount of anticholinergic side effects caused by the belladonna alkaloids.

Rectal suppositories are generally preferred to parenteral dosage forms because the former drugs allow some degree of patients maintaining control of their drug administration.

Narcotic Dosing

The importance of regularly scheduled dosing of analgesic drugs for patients with severe, chronic pain due to a physical cause has been emphasized previously. It is important to remember that most nurses, physicians and pharmacists were educated and trained to believe that narcotics should only be used when pain is excruciating, and then only on a "prn" basis. Therefore, reeducation of caregivers becomes a priority in assuring appropriate dosing regimens. It is important to remember to include night nurses in the educational process. Too often, a patient's long standing pain is finally controlled with regularly scheduled, around-the-clock narcotic doses, and a new night nurse discourages a midnight dose of drug due to obvious symptom control. The result can be a patient who awakens at 4:00 a.m. in agony. The patient's anxiety level increases dramatically as a result and all progress to date is lost.

It is also essential to educate many patients about the necessity to take their narcotic drugs on a regular basis. Many patients and family members refuse doses until pain is severe because they believe that this is the only "right" way to use narcotics. Many have fears of inducing drug dependence. Others believe that pain should be borne stoically, not lessened with drugs. A useful analogy in reeducating these patients is the use of penicillin for the common cold. It is as wrong to take penicillin for a cold as it is to take narcotics for trivial pain. It is as correct to take the narcotics on a regularly scheduled basis for severe, chronic pain of a physical origin as it is to take a full course of penicillin for streptococcal pharyngitis.

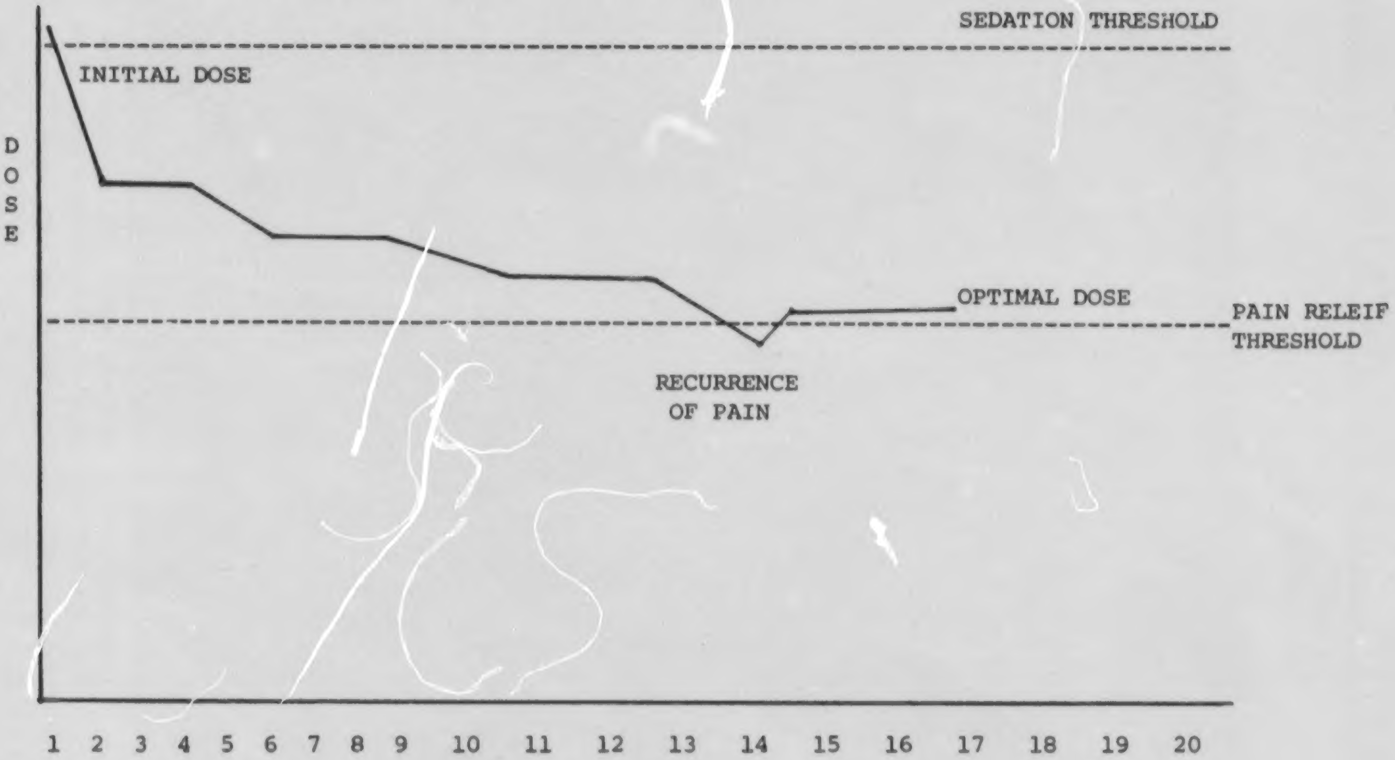
When narcotic analgesic therapy is initiated, it is usually necessary to start with a high dose. If narcotics are used and pain control is not achieved rapidly, the patients' anxiety levels often rise rapidly due to fear that pain control is not achievable. It is, therefore,

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | preferable to mildly overdose than to underdose initially. Many nurses and physicians have undue fear of inducing coma or respiratory arrest with aggressive narcotic dosing. Central nervous system depression due to narcotics proceeds in a straight line relationship from the highest CNS centers (thought integration) to the lowest (respiration). Therefore, mild obtundation is not indicative of impending respiratory collapse. Period monitoring of vital signs is in order to continually assess the CNS depression of a patient who is receiving initial, aggressive narcotic analgesic therapy. For patients whose respiratory function is already compromised, hospitalization (when an inpatient hospice facility is not accessible) may be adviseable for initial dose titration. Many patients' pain can be controlled at home with appropriate nursing supervision.<br>When patients' longstanding pain is initially controlled, it is common for them to sleep for many hours. Twelve hours of sleep is common. As much as 30 hours of sleep has occurred. This sleep is not usually indicative of an overdose of narcotics if the vital signs are normal or in the low normal range. Rather, the sleep is in response to a sleep deficit that the patient has developed. Severe pain usually precludes adequate sleep. Initiation of analgesia allows the deficit to be corrected.<br>Appropriate narcotic analgesic dose titration is presented graphically in Figure 8. The vertical (Y) axis of the dose-response curve represents the dose (or blood level) of the drug. The horizontal (X) axis represents time in days. The lower dotted lines represents the dose (or blood level) below which analgesia is not accomplished. The upper line is the level above which the incidence of side effects becomes troublesome.<br>The optimal dose of narcotic analgesic is the lowest dose at which pain control is accomplished. The optimal dose may be found by starting with a dose which is estimated to be in the higher end of the therapeutic range. If the initial dose is too high (as illustrated in Figure 9), the second dose should not be given until the sedation has lessened. The subsequent doses should be decremented every five half-lives of the drug. For morphine, decrements every two days would be appropriate. More frequent decrements would lower the dose before |

FIGURE 8

NARCOTIC DOSE TITRATION

(From reference 9)



| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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steady state serum levels are achieved. This might lead to loss of pain control.

If the initial dose is too low to provide analgesia, rapid and aggressive dose increments should be undertaken until an effective dose is achieved. Small or gradual increments are not adviseable since such increases favor mounting anxiety by the patient.

The dose of narcotic should be continually decreased in small decrements until either the drug is no longer needed or until pain returns. It is usually adviseable to discuss the dose titration plan with the patient once pain control is achieved and before the decrements are initiated. This is to assure that the patient reports the time at which pain control is lost. In particularly anxious patients, it is sometimes not adviseable to discuss the downward titration of drug lest this exacerbate fear of pain returning. In most patients, however, once the pain is initially controlled, the caregivers find the patients to be receptive to suggestions and cooperative.

It is important to decrement the dose. The initial dose may provide analgesia, but if it is higher than necessary, the dose may cloud the patient's sensorium, impair coordination, cause abberant thinking and cause drug dependence. The optimal dose is not the dose at which pain is eliminated. It is the dose at which pain is at a level which the patient can tolerate. The optimal dose may remain steady for a long period. More commonly, the dose will increase or decrease as the underlying pathology shifts. Continual titration of dose to response is necessary to maintain optimal therapy.

Dose increments and decrements are often determined by the availabe dosage forms. Methadone HCl (Dolophine®, Eli Lilly and Company) is available as five and ten mg tablets, each with a single score. Therefore, one-half of a five mg tablet equals 2.5 mg and this is the lowest convenient dosage strength shift. An oral morphine solution was introduced in March 1980 (Phillips-Roxane Laboratories). This bland solution contains two mg per ml, permitting small dosage changes with ease. When oral liquids are prepared extemporaneously by pharmacists, bland vehicles should be used. The cherry syrup commonly used for such formulations is poorly tolerated by many patients with advanced cancer. Taste changes are common in advanced disease.

The major physiological function that should be monitored is renal function. It is not necessary to obtain laboratory reports of BUN and creatinine levels to do so. If the quantity or quality (clarity, odor) of the patient's urine decreases noticeably, dose reductions due to decreasing renal excretory capacity may be necessary. Patients should be monitored for alertness and mood changes that may be due to narcotic accumulation.

A common cause of pain recurrence is patients' refusal or failure to take their analgesics on a regular basis. If patients prefer pain to taking narcotics, that is their prerogative. It is the health professionals' responsibility to explain the options to the patient and to encourage maintenance of symptom control for the benefit of the patient and his/her family. Nurses should be creative and innovative in helping patients to remember to take their drugs as prescribed. A simple listing of drugs with the appropriate administration times may be helpful (figure 10) Such a card may be filled out by the nurse to advise patients of appropriate dosing times. Alternatively, a pad of these cards may be given to the patient to allow him/her to titrate and record the doses. Some patients benefit greatly from being allowed to help determine their own optimal doses and dosing times. Patients who are "intelligent noncompliers" often do a better job of determining optimal doses than do experienced health professionals.

There is no rationale to mixing of narcotic analgesics. If a long acting drug is not preventing pain recurrence between regularly scheduled doses, it is not appropriate to add a shorter acting drug for intermittent prn doses. Rather, the dose of the long acting drug should be increased. Narcotic analgesics are metabolized and excreted according to the laws of first order pharmacokinetics. This means that as the dose increases, the duration of action increases. In most patients, an increased dose will produce a longer duration of analgesia. Some patients will metabolize and excrete narcotics more rapidly than others. Therefore, it will be necessary to administer the drugs to some patients more frequently than to most other patients. The potential for accumulation as described above should be kept in mind

FIGURE 10

MEDICATION SCHEDULE OF________________________________ DATE:            BY:

| DRUG/STRENGTH | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | COMMENTS |
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whenever the dosage interval is decreased.

There is no advantage to using more than one narcotic concurrently because all of the drugs act via the same mechanism. A few people are allergic to the naturally occurring drugs, e.g., morphine. For these patients, a synthetic drug is preferrable, e.g., methadone.

Routes of Administration of Narcotics

Oral administration is nearly always preferred to parenteral administration of narcotics. It is important to allow patients with irreversible disease to maintain as much control of their lives as possible. Furthermore, injections carry a connotation of heroic measures. The rectal route is the alternative of choice for patients unable to take drugs orally.

In acute pain management, parenteral analgesics are used to provide rapid serum levels. When the drugs are administered on a regular schedule to maintain blood levels, there is no pharmacological advantage of injections over oral therapy. In fact, oral dosing is preferred since it provides lower peaks and longer duration of action (Figure 11) than injections of the same dose of drug (Figure 12).

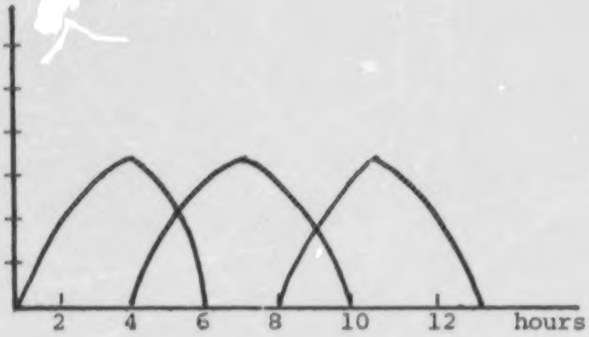
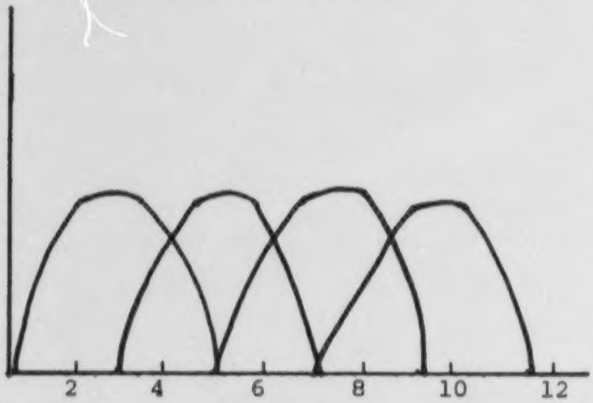


Figure 11 Oral dose response curve

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | <br> <br>Figure 12 IM dose response curve<br>Both intermittent and continuous intravenous infusion of morphine have been effective in controlling severe pain associated with cancer. This route of administration may provide excellent pain relief in patients who have advanced disease and in whom drugs cannot be administered by other routes. Intravenous infusion has been used successfully in children as described by Miser et al.[19]<br>Miser et al. paper[8] |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Recently, there has been increasing literature on the usefulness of administering narcotics intrathecally for refractory pain.[20] This route deserves consideration only when administration by other route does not provide adequate pain relief. Preliminary experience with intrathecal morphine in cancer patients has been described by Wang et al.[21]<br>Wang et al. paper.[9] |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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### Narcotic Analgesic Myths

Several myths about narcotic analgesics have arisen. Some of these myths have resulted in less than optimal therapy, avoidance of good drugs and inappropriate beliefs about narcotic analgesics.

### Heroin

There is a large controversy over the nonavailability of heroin as a legitimate medical drug in the United States.[22] The Washington, DC based National Committee for the Treatment of Intractable Pain is an active political lobby and public opinion group that is advocating the legalization of heroin as a legitimate drug. In November 1977, President Carter formed the Committee on New Therapies for Pain and Discomfort, partly to look into the propriety of heroin becoming a legitimate drug in this country. Controlled trials of heroin as an analgesic are now being initiated by the National Institute on Drug Abuse (NIDA).

All of this is unfortunate because the scientific evidence now available indicates that there is no need for heroin. This issue was well summarized in the Journal of the American Medical Association in October 1980.[23]

Lewis Commentary[10]

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | The definitive study on this question was published by Twycross in 1977. Twycross demonstrated in a controlled trial of heroin and morphine that the former drug does not offer a pharmacological advantage over the latter in the treatment of terminal cancer pain.[23]<br>Twycross Paper[11]<br>Twycross does make a case for heroin as an injection due to the drug being more soluble than commercially available morphine sulfate. This allows a high dose to be dissolved in a small volume of dilutent. In patients with diminished muscle mass, a smaller volume injection is a definite advantage. Morphine acetate solution offers the same advantage of high solubility. Morphine acetate solution is available from the National Institute on Drug Abuse and may become commercially available in this country in the future.<br>The real potential for abuse and diversion of heroin and the lack of advantage of heroin over commercially available narcotic analgesics mediate against efforts to study heroin further and to make it commercially available.<br>Analgesic Cocktails and Cocaine<br>The Brompton Cocktail has been attributed almost magical powers during the past 15 years. Scientific study of the efficacy of Brompton's Cocktail and other highly touted narcotic mixtures and of heroin has only begun in earnest in this decade. As recently as 1970 leading European[25] and North American[26] clinicians were advocating the use of Brompton's Cocktail as the analgesic of choice in advanced cancer pain and a noted political columnist was demanding that heroin be legalized for analgesia in the United States.[18] There is no scientific foundation to the claims of superior efficacy of these drugs. A recent controlled trial has shown that the addition of cocaine does not increase the efficacy of narcotics and may cause dysphoria.[27]<br>The use of narcotic containing multiple drug cocktails in severe pain dates from the late 19th Century when Snow, a surgeon at the Cancer Hospital, London (now the Royal Marsden Hospital), reported the use of morphine and cocaine in advanced cancer.[28] He later deleted the cocaine due to its expense. In the 1920's, Roberts, a surgeon at the Brompton Hospital in London, |

reintroduced a morphine-cocaine mixture for analgesia following thoracotomy. Other combination analgesic formulations became popular in later years and in 1952 the Brompton Hospital published a pharmacopoeial supplement containing the following formulation named "Haustas E."[29]

| | |
|---|---|
| Morphine HCl | 15 mg |
| Cocaine HCl | 10 mg |
| Alcohol 90% | 2 ml |
| Syrup | 4 ml |
| Chloroform water q.s. ad | 15 ml |

Later formulations substituted diamorphine for the morphine. Such formulations have been called Hospice Mix, Saunder's Solution, Euphoriant Solution, and Brompton's Mixture. It should be noted that the real Brompton Mixture is a cough preparation, not an analgesic, and it contains morphine, hydrocyanic acid, syrup of tolu and flavoring.[29] The formulation commonly referred to as the Brompton Cocktail (sometimes mixture) is currently called Haustas E. The British Pharmacopeial Codex of 1973 included diamorphine and cocaine elixir. This formulation was listed in an effort to standardize the several opiate-cocaine formulations then being used in the United Kingdom. Several opiate combination formulations have come into use in the United States in recent years. Most are irrational, expensive, and unncessary. Unfortunately, public groups and state and federal legislatures are still attempting to legalize heroin for use as an analgesic in this country. Heroin offers no therapeutic advantage over the commercially available narcotic analgesics. But because of its ability to produce a euphoric "rush" following intravenous administration, the abuse of heroin and the potential for the diversion of the drug into illicit channels is great.

Cocaine is not addictive to the analgesic effect of narcotic analgesics as reported in a recent controlled double-blind study.[27] Cocaine was added to the original Brompton's Cocktail as a local analgesic for the throat and/or to relieve some of the sedation produced by the narcotic. The former suggested indication may be appropriate in some pulmonary disease patients (the Brompton Hospital is an institution primarily for chest disease), but is not applicable to most pain

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | patients. The later indication is not appropriate because titration of the narcotic dose, as described above, results in minimal sedation from the analgesic. |
| | A third component of many opiate cocktails is alcohol. Alcohol is an additive central nervous system depressant to the narcotic, but the addition of the alcohol offers no pharmacological or therapeutic advantage. Since the narcotic dose is titrated to effect, the addition of alcohol may allow the use of less narcotic, but the alcohol provides no advantage in safety or efficacy. |
| | The fourth common ingredient of many British opiate mixtures in the past has been chloroform water. This agent was added to impart a medicinal taste. Chloroform has been implicated as a carcinogen and has been removed from the U.S. list of materials generally regarded as safe (GRAS list) for use in foods and drugs. |
| | The British sociological expectation of many drugs is that they be in bitter or "medicinal" tasting liquids. Thus, the opiate cocktails meet British, not American expectations. |
| | Twycross discusses the Brompton Cocktail further and discusses the use of this formulation in treating severe cancer pain.[30] |
| | Twycross paper[12] |
| | The fact that the Brompton Cocktail offers no advantage over simple morphine was demonstrated in a controlled, double blind cross-over trial by Melzack, Mount and Gordon.[33] |
| | Melzack et al. paper[13] |

### Oral Morphine

Morphine is available in oral and parenteral dosage forms. There is a common belief that morphine is poorly absorbed following oral administration and therefore is not a good oral drug. Morphine is only about two-thirds absorbed following oral administration,[31] but it is consistently absorbed. Therefore, 15 mg of oral morphine produces similar activity to 10 mg of the drug administered by subcutaneous or intramuscular injection. Clinical experience with oral morphine at several hospices has shown it to be an effective, consistent drug.

### Narcotic Dependence and Tolerance

Narcotic analgesics are known to induce both tolerance and dependence when administered to patients with acute pain, to subjects seeking a "high" and to individuals with pain of a psychological origin.

Drug dependence in patients treated with narcotic analgesics is rare. Porter and Jick reported that of 39,946 hospitalized medical patients who were studied, 11,882 received at least one narcotic preparation and there were only four cases of reasonably well documented addiction in patients who had no history of addiction.[32]

It is possible that patients in advanced chronic pain have different biochemical and pharmacological responses to narcotics than do other people. Preliminary endorphin studies suggest that acute and chronic pain produce different release patterns for endorphins.[34] If patients who have chronic pain due to a physical process have more highly activated endorphin systems, it is reasonable that such patients require high doses of narcotics to achieve pain relief and respond differently to the exogenous opiates. This may be due to the patients' opioid receptor sites being bound by relatively inefficient endorphins or to inefficient receptors. In either case, massive quantitites of exogenous opiates may be needed to displace the relatively ineffective endogenous opioids from the binding sites.

Twycross has documented that tolerance and physical dependence are not practical problems in patients with pain due to advanced malignant disease who were treated

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | with heroin.[25]<br>Twycross Paper[14]<br>The exact reasons for dependence and tolerance not being problems for patients treated with narcotics as described in this module are not known. Extensive clinical experience has demonstrated that patients with severe, chronic pain due to advanced, irreversible cancer are able to obtain excellent pain control with minimal clouding of the sensorium and without tolerance or dependence developing when the narcotic analgesics are used appropriately. |

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

## Communicating About Pain and Disease

Family members, caregivers and friends of patients frequently avoid discussing the disease, its symptoms and its prognosis with the patient. When a patient is actively denying his or her disease, this may be appropriate. Frequently, however, patients strongly sense or know what is happening in their bodies. In such cases, refusal to discuss the disease openly and honestly can seriously exacerbate the patient's anxiety and thus the pain.

Communication with patients is a major part of a separate module. It is important for trainees to appreciate that refusal to discuss terminal illness and to discuss the prognosis of the disease when the patient is ready to do so more often complicates the management of symptoms.

Patients usually ask if the disease is terminal in oblique ways such as "Will I be able to attend my niece's high school graduation next June?" An honest answer of "I don't know" with an appropriate discussion of the prognosis of the disease is nearly always preferable to a dishonest "of course" when the probability is doubtful.

Likewise, telling a patient how well he or she looks when it is perfectly obvious to the patient that he or she is becoming physically devastated may be very harmful. Anxiety is fear of the unknown. Not infrequently, the patient feels much better physically after an honest discussion of the fact that the disdisease is irreversible.

Skillful listening and responding by all caregivers is an essential component of effective symptom control. Responses should address appropriate beliefs and correct inappropriate ones. Patient's fears of physical disfigurement that do not in fact occur can exacerbate anxiety greatly.

It is also important that caregivers realize that patients' will choose with whom they wish to discuss their concerns. A physician may resent the patient discussing pain more openly with a homemaker than with the physician. However, patients frequently are

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | unable to discuss matters with persons to whom they feel indebted or upon whom they feel dependent. Communication among all caregivers is important to help diminish the patients' anxiety as expressed in conversation and offhand comments.<br>Nausea and Vomiting<br>Cancer patients frequently complain that the symptoms of their disease are more bothersome than the knowledge of their having the disease. Symptoms continually remind patients of the pathology and thus symptoms often preclude patients denying the disease at times when they would like to forget about it for a while.<br>Nausea and vomiting are second only to pain as the symptoms which patients consider highly disturbing. Nausea and vomiting are exacerbated by many of the therapeutic measures undertaken to induce remission, lower the tumor load or provide temporary relief from other symptoms of cancer.<br>An open discussion with the patient of which therapies are apt to induce or exacerbate nausea and vomiting is in order. When patients understand that nausea is an unavoidable accompaniment of certain therapies and that the nausea is usually self-limiting, they are often better able to bear the symptom. Many patients actually welcome a low degree of nausea as an indicator that neoplastic cells are being destroyed. It is therefore sometimes useful to explain the nausea and vomiting as a very common symptom of cell death. Since destruction of cancer cells is the objective of antineoplastic therapy and because most therapies are not specific for cancer cells, i.e., all rapidly proliferating cells are at risk - including the cells that line the gastrointestinal tract-destruction of rapidly proliferating noncancer cells is a common accompaniment of the destruction of cancer cell. Therefore, antineoplastic therapy commonly causes adverse symptoms due to the destruction of these normal cells. Such symptoms include:<br>● Depression of blood elements<br>- leukocytes |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

  - platelets
  - erythrocytes
- Nausea and vomiting
- Alopecia
- Decreased gonadal functions
  - decreased libido
  - impotence
  - sterility

The etiologies of nausea and vomiting in patients with advanced disease may be variable and multiple. The therapeutic approaches may also be varied. Examples of common causes and treatment are listed in the following table.

NAUSEA AND VOMITING

| Etiology | Treatment |
|---|---|
| Disease | Induce remission<br>Treat at source |
| Antineoplastic Drugs | Phenothiazines before treatment |
| Radiation Therapy | Phenothiazines before treatment |
| Salicylates | Antacids with salicylate doses |
| Steroids | Antacids with steroid doses |
| Narcotics | Phenothiazines plus antihistamines |
| Uremia | Stop drugs when possible<br>Dietary control, Antiemetics |
| Elevated Intracranial Pressure | Osmotic diuretics<br>Glucocorticoids |

The disease itself is a common cause of nausea and vomiting. When the gastrointestinal tract is compressed by tumor mass, inability to eat is a common occurrence. Patients who have such tumors may report non-projectile regurgitation of foods soon after eating. This effect may be due to the food mass reaching the tumor mass, being unable to pass the block and therefore being regurgitated. Relief of vomiting due to such physical block is normally accomplished by removal of the block. Such surgery may be very helpful even in advanced disease.

Both antineoplastic drug therapy and radiation therapy are commonly associated with severe nausea and vomitign. These symptoms are often unavoidable and patients often cope better with the nausea and vomiting when they are advised of the possibility of the symptoms occurring. Antiemetic drug therapy is often helpful. Initiation of the therapy several hours before the treatment and maintenance of the antiemetic doses for the normal duration of the nausea, e.g., 30 hours, on a regular schedule is advised. Because the symptoms may not occur until several hours after a treatment, patients usually do not take the antiemetic until after the treatment. Initiation of antiemetic therapy before the treatment may lessen the symptoms several hours later.

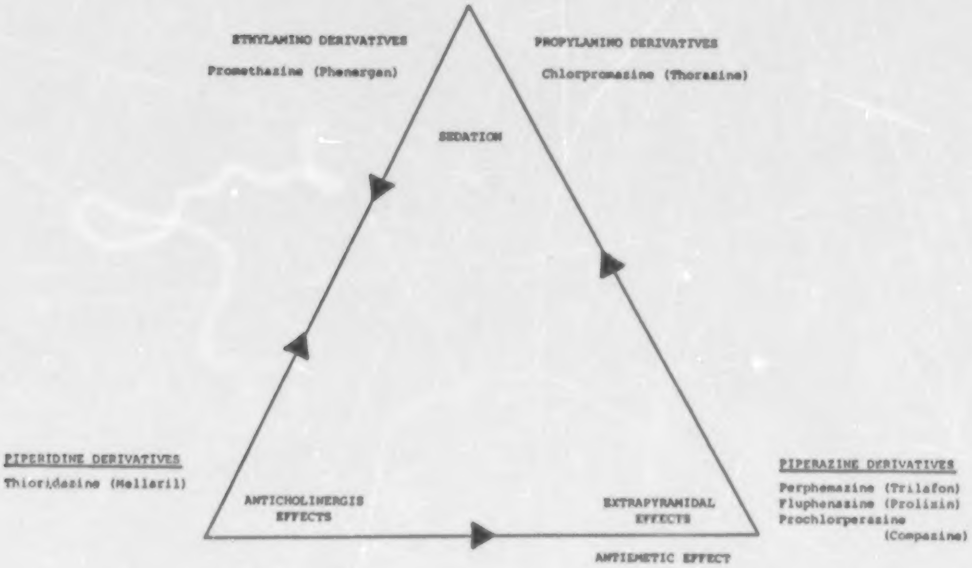
The antiemetic drugs of choice are normally phenothiazines. This class of drug is employed primarily in schizophrenia. Therefore, patients and their families should be advised that the drug is being used for nausea, not as an antipsychotic agent, lest inappropriate inference be made.

Phenothiazines are subdivided by the chemical side chains on the molecule nucleus. The three principal categories are the alkylamino group, the piperidine group and the piperazine group. Certain desired and adverse effects are associated with each group as illustrated in Figure 13.

The alkylamino group is the most sedating and has good antiemetic activity. The piperazine group has the most antiemetic activity, the least sedation potential and the highest incidence of extrapyramidal effects, and the piperidine side chain group is associated with

Figure 13

EFFECTS OF PHENOTHIAZINES ACCORDING TO SIDE CHAINS


ETHYLAMINO DERIVATIVES
Promethazine (Phenergan)
PROPYLAMINO DERIVATIVES
Chlorpromazine (Thorazine)
SEDATION
PIPERIDINE DERIVATIVES
Thioridazine (Mellaril)
ANTICHOLINERGIS EFFECTS
EXTRAPYRAMIDAL EFFECTS
PIPERAZINE DERIVATIVES
Perphenazine (Trilafon)
Fluphenazine (Prolixin)
Prochlorperazine (Compazine)
ANTIEMETIC EFFECT

a high degree of anticholinergic effects and the least antiemetic activity. The piperazine group is therefore the group of choice for antiemetic drugs since patients are frequently sedated from their narcotics. An alkylamino side chain drug, e.g., chlorpromazine, may be preferred for a highly agitated patient in whom sedation is desired or for a patient who has preexisting extrapyramidal symptoms.

Prochlorperazine (Compazine) is the most commonly used phenothiazine antiemetic. This drug is available in a variety of dosage forms including rectal suppositories. Low doses are indicated, e.g., 5 mg three times daily. Higher doses are associated with a bothersome incidence of anticholinergic effects, extrapyramidal effects and dysphoria. Rectal suppositories are poorly absorbed. The rectal dose should be two to five times higher than the oral dose for similar activity.

Narcotic analgesics commonly cause nausea. The major mechanism for this effect is believed to be stimulation of the chemoreceptor trigger zone (CRTZ, CTZ) in the medulla oblongata. This is believed to be the site of action of the phenothiazines. Narcotics may also cause nausea by stimulating the vestibular apparatus of the inner ear.

Narcotic induced nausea often responds to phenothiazines alone. When the nausea is not adequately relieved by a phenothiazine, especially when the symptom is associated with or exacerbated by motion, an antiemetic-antihistamine adjunct may be helpful. Low doses of these drugs, e.g., meclizine, 25 mg two times a day in addition to the low dose phenothiazine may provide relief. Clinicians should be aware that both the phenothiazines and antihistamic antiemetics have anticholinergic activity and that these effects are additive.

Intractable nausea and vomiting not infrequently necessitate hospitalization of patients who would otherwise be able to remain at home. This can sometimes by avoided if the patient modifies his/her normal activities according to his/her more limited capabilities as the disease progresses. An example was Mrs. R., a 72 year-old lady whom I met at an outpatient clinic. She had moderately advanced carcinoma of the liver but seemed to be responding well to symptomatic treatment of her pain and nausea and was living a relatively normal life at home. One week after Mrs. R. was seen in clinic, she was admitted as an inpatient complaining of severe nausea and vomiting despite her receiving regularly scheduled doses of prochlorperazine and cyclizine. As she discussed her problem with the staff the next day, Mrs. R. noted that her nausea was most bothersome when she was preparing meals for her husband and herself. He had urged her to allow him to do the cooking, but she wished to maintain as much normality in their lives as possible. At our request, Mrs. R. agreed to share the task of preparing meals with Mr. R. and a neighbor. She went home two days later and was not troubled by the nausea again for an extended period of time.

Many patients' kidney function decreases as their diseases progress. The onset of anemia may be insidious and nausea is sometimes an early sign of poor kidney function. Uremic patients have difficulty excreting many drugs and the accumulating metabolites may exacerbate nausea. Unnecessary drugs should be stopped and doses of necessary drugs should be lowered when possible. Dietary control of the uremia should also be considered since certain foods may cause nausea in uremic patients.

One other cause of serious nausea and vomiting is elevated intracranial pressure due to brain tumor or metastases. Antiemetic drugs are of little value in such cases. Decompression of the brain with intravenous glucocorticosteroids or intravenous mannitol is very helpful.

Recently, there has been a growing interest in the use of delta-9-tetrahydrocannabinol (Δ-9-THC) the active ingredient in marijuana, as an antiemetic in severe nausea and vomiting caused by antineoplastic chemotherapy.[35-40]

The component of marijuana that provides most of the antiemetic activity is Δ-9-THC. It is available as an investigational drug through the National Institute on Drug Abuse in the form of soft gelatin capsules for oral use. Marijuana cigarettes are also available

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | from that agency for investigational use.<br>Marijuana and Δ-9-THC have been shown to be useful in managing nausea and vomiting induced by certain antineoplastic agents. In most patients, Δ-9-THC is probably no more useful than prochlorperazine.[35]<br>Frytak et al. paper[15]<br>In some patients who did not respond to the phenothiazine, Δ-9-THC has been effective. The converse may also be true. One major drawback to -9-THC is that patients must frequently be "stoned" by the drug, i.e., suffer the psychological effect of marijuane, before they receive the antiemetic benefits. Many patients may prefer being nauseated to being stoned.<br>A review of this drug was provided by the Medical Letter.[40]<br>Medical Letter Review[16] |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

Several synthetic cannabinoids have also been developed.[82] Nabilone is such a synthetic derivative of Δ-9-THC. Nabilone has been shown to be superior to prochlorperazine as an antiemetic in patients receiving cancer chemotherapy.[41] Due to nabilone associated seizures and deaths in animal studies, clinical testing was suspended in 1979. Further cannabinoid studies will undoubtedly be forthcoming and these synthetic derivatives may offer advantages over Δ-9-THC.

When patients ask about marijuana for nausea, it is now appropriate to inform patients about the current lack of a definitive answer to the place of Δ-9-THC in chemotherapy induced nausea. It is probable that ongoing studies will provide answers to this question in the foreseeable future.

Diarrhea and Constipation

Both advanced diseases and the drugs used to treat them may have profound effects upon bowel function. The colon is a major conservator of fluid and electrolytes in the body. The importance of good bowel function is increased when renal function is impaired.

Diarrhea occurs far less frequently than constipation in patients with advanced disease who are receiving narcotics. As with all symptoms, it is important to attempt to identify and treat the cause rather than simply to treat the symptoms.

Diarrhea induced electrolyte deficiencies can cause depression and fatigue. Most electrolyte deficiencies can be rectified through continued small sips of an oral electrolyte solution.

Nonspecific diarrhea may be treated with standard antidiarrheal preparations. The opiate derivatives are much more effective than the adsorbant-astringent gels. When patients are already receiving full doses of narcotics, it is doubtful that opiate antidiarrheal drugs will be effective.

Patients sometimes develop fecal mass impactions which partially occlude the colon. In such cases, watery waste may pass around the mass and present as diarrhea when in fact, the problem is constipation. Use of

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

antidiarrheals in such patients is dangerous and is contraindicated.

Constipation is a very common complaint due to both anticholinergic and direct impedence of gastrointestinal motility. Hydration is important in helping to prevent or minimize constipation. A glass of a beverage that the patient likes should be kept handy with a straw if necessary and the patient should be encouraged to take drinks frequently.

There are five classes of laxative drugs available. These are:

| Class | Example |
|---|---|
| bulk producers | psyllium (Metamucil) |
| saline cathartics | Milk of Magnesia |
| stool softeners | dosucate (Colace) |
| peristaltic stimulants | bisacodyl (Dulcolax) |
| lubricants | mineral oil |

The bulk producers are the drugs which most closely induce normal bowel activity. These drugs are preparations which absorb water, swell and produce gentle pressure on the intima of the intestines. This pressure induces peristaltic activity which results in evacuation. Bulk producers are the preferred laxatives for most patients with mild constipation. This class of drugs produces the lowest risk of inducing dependence and cathartic colon. Bulk producers often are not effective when peristaltic activity is inhibited due to narcotics or anticholinergics. Therefore, this class of laxatives may be useful in early disease, but may be of little value in advanced disease. Bulk producers frequently require 24 to 72 hours to act.

The saline cathartics act by introducing a hypertonic solution into the intestines. Thus, water is drawn into the lumen to establish equivalent tonicity between the intraluminal fluid and fluid in other body compartments. Both pressure and lubrication within the lumen thereby increase. Saline cathartics commonly contain magnesium and/or sodium. Both of these electrolytes can be adsorbed and magnesium must be used with great caution in patients with impaired renal function. Many patients with advanced disease are

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | edematous, especially if they are receiving glucocorticosteroids. In such patients, excessive salt intake should be discouraged. Saline cathartics normally act in 12 to 24 hours. Saline cathartics are used both orally and rectally (e.g., Fleets Enema).<br>The stool softeners are essentially detergents which act by increasing the water content of the stool. More recently, there have been suggestions that these drugs act by causing an isotonic secretion in the intestines which decreases stool consistency. The advantage of stool softeners over several glasses of water a day has been questioned. Stool softeners are of doubtful value in patients with advanced disease.<br>The peristaltic stimulants cause direct irritation of the intestines which increases peristaltic activity. Most vegetable and fruit laxatives, e.g., senna, prunes, act in this way. Castor oil contains an irritating constituent, ricinoleic acid. These are the most potent laxatives. They are also associated with the highest incidence of dependence and cathartic colon. These drugs are frequently combined with stool softeners. The advantage of the stool softener in such combinations is questionable. Peristaltic stimulant suppositories act rapidly, but may induce evacuation of only the distal colon. Tablets or liquids may take from four to 12 hours to act. Enteric coated tablets should not be taken with milk or antacids since basic materials may result in dissolution of the enteric coating and destruction of the drug by stomach acid. When constipation is severe, peristaltic stimulants are often the drugs of choice.<br>The lubricants act by lubricating the surface of the stool to aid evacuation. Digestible oils, e.g., corn oil are less effective than mineral oil. Rectally, glycerin suppositories as well as mineral oil enemas are useful. Lubricants are useful in patients who have hard, dry stools which are difficult to pass. Combinations of mineral oil and saline cathartics (e.g., Haley's MO) are available, but do not appear to offer an advantage in patients with advanced disease. Only heavy mineral oil, not light mineral oil, should be used as a lubricating laxative because light mineral oil tends to "leak" from the rectum. |

Dietary control and prevention of constipation is preferred to drugs. When drugs are needed, the peristaltic stimulants are frequently required.

Adjunctive Steroid Therapy

Glucocorticosteroids are useful antineoplastic agents in certain leukemias, lymphomas and as adjuncts in a variety of other cancers. The glucocorticoids have also been associated with a variety of symptomatic benefits for patients with advanced cancer. These claimed benefits include:

sense of well being
improvement of appetite
weight gain
resolution of weakness
relief of dyspnea
lower narcotic requirement for pain control
lessening of hypercalcemia

Euphoria and alleviation of anorexia are commonly associated with initiation of glucocorticosteroid therapy. The exact mechanism of these effects is unknown. Weight gain may be associated with improved appetite and with fluid retention due to the mineralocorticoid activity of the steroid. Although drug induced edema is generally not desirable, mild water retention is usually not harmful and the psychological advantage of the weight gain can be great. The anti-inflammatory activity of the steroids may relieve labored breathing and provide some pain relief. Steroids stabilize the basement lysosomal membranes of cells thereby preventing the release of noxious endogenous chemicals such as bradykinin into surrounding tissues. The steroids also affect calcium metabolism. The lessened hypercalcemia may also contribute to pain control in patients with painful bony metastases.

Prednisone is the most common glucocorticosteroid used because it is relatively inexpensive and possesses only moderate mineralocorticoid activity. The relative anti-inflammatory and mineralocorticoid activities of several steroids are listed in the following table:

| Steroid | Physiological dose | Relative anti-inflammatory potency | Relative Mineralo-corticoid activity |
|---|---|---|---|
| cortisone | 25 mg | 0.8 | ++++ |
| hydrocortisone | 20 mg | 1 | ++++ |
| prednisone | 5 mg | 4 | ++ |
| prednisolone | 4 mg | 5 | ++ |
| dexamethasone | 0.75 mg | 25 | + |

The potential benefits of corticosteroids in terminal cancer patients greatly outweigh the potential risks. The effect of corticosteroids in terminal cancer patients was documented by Schell in 280 cancer patients who received corticosteroids and 235 who did not. A broad range of neoplasms was included. Post-mortem examinations were performed on all patients and the history, physical examination, laboratory studies and clinical course of each patient were reviewed. Only in the incidence of gastrointestinal ulcer did the corticosteroid recipients show a higher incidence of adverse effects.[42,43] These data are presented in the following table. The ulcers were largely asymptomatic.

Prednisone in single daily doses of 5 to 15 mg is most commonly used for such symptomatic relief. Steroid therapy in this manner is not advocated for patients whose prognoses are unclear due to potential adverse effects of the drugs. When the prognosis is three months of remaining life or less, steroids may be helpful.

Administration of corticosteroids to terminal patients has been shown by Twycross to increase survival time. Four hundred and twelve patients with a prognosis of less than 13 weeks received corticosteroids while 421 similar patients did not. During the first four days after admission 12% of the corticosteroid recipients died compared to 27% of the non-recipients. Forty-six percent of the corticosteroid recipients lived for more than 28 days compared to 24% of those not receiving corticosteroids. Both differences are highly statistically significant ($p < 0.001$). Although these data are from an uncontrolled study of two unmatched populations, the data suggest that patients who receive steroids for symptomatic reasons live longer, perhaps because of better symptom control. (Figure 14)

## EFFECTS OF STEROIDS IN TERMINAL CANCER PATIENTS

## ON AUTOPSY

(According to Schell)

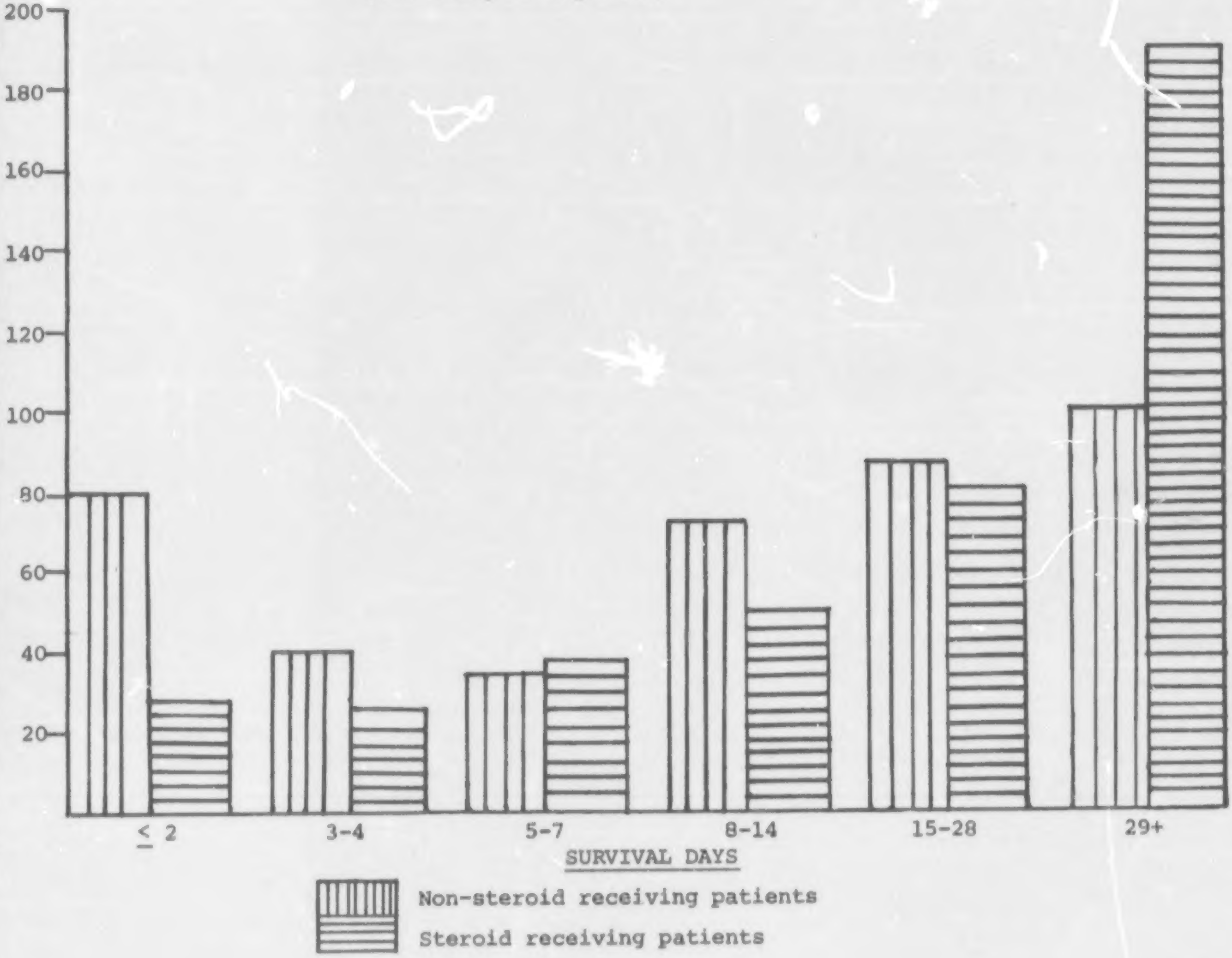
| | Steroids (280 patients) | No Steroids (235 patients) | Statistical Analysis* | |
|---|---|---|---|---|
| Gastrointestinal Effects | | | | |
| Ulcer, Active | 10.0% | 3.0% | significant $p<0.01$ | (3.14) |
| Ulcer, Complicated | 5.0% | 0.9% | significant $p<0.01$ | (2.59) |
| Esophagitis | 3.6% | 3.0% | N.S. | (0.42) |
| Active Infection | | | | |
| Pulmonary (not TB) | 62.0% | 65.0% | N.S. | (0.70) |
| Tuberculosis | 0.7% | 1.3% | N.S. | (0.69) |
| Pyelonephritis | 15.0% | 15.0% | N.S. | (0) |
| Endocarditis | 1.4% | 0.4% | N.S. | (1.15) |
| Diabetic Complications | - | - | N.S. | (0) |
| Pulmonary Embolism | 13.6% | 11.2% | N.S. | (0.82) |

Reference: Geriatrics, 27:131-141, (January) 1972

*significant if $\geq$ 2.58
binomial distribution,
two tailed $p=0.01$

COMPARATIVE HISTOGRAM OF PATIENT SURVIVAL

(According to Twycross)



Thus, corticosteroids appear to have both specific and nonspecific benefits in the management of terminal illness. Corticosteroids may improve both the quality and quantity of the life remaining to a patient with a terminal prognosis.

Iatrogenic Symptoms

Throughout this module, reference has been made to the risk of inducing adverse symptoms by administering drugs to treat the disease or other symptoms.

A list of identified symptoms and drugs which can induce or exacerbate these symptoms is presented at the beginning of this module (p. 5).

Anticholinergic (parasympatholytic) effects are common and may be serious. Several classes of drugs used to treat symptoms of advanced disease, all of which have anticholinergic activity, include the following:

| Drug Group | Uses |
|---|---|
| Phenothiazines | Narcotic adjuncts<br>Sedatives<br>Antianxiety agents |
| Tricyclic Antidepressants | Antidepressants |
| Antihistamines | Antiemetics<br>Symptomatic agents |
| Anticholinergic Agents | Antisecretory agents<br>GI hypermotility |

Anticholinergic effects include:

- blurred vision due to reduced visual accommodation
- urinary retention
- constipation
- dry mouth and mucous membranes

Anticholinergic side effects can be particularly troublesome in terminal patients. Dry mouth is uncomfortable and can interfere with verbal communication when a patient finds it very necessary to talk about feelings. I knew a Mr. C., a 72 year-old man with advanced carcinoma of the stomach who complained of severe dry mouth. He always had a pipe next to his bed, but I'd never seen him smoke it. When I asked if he smoked he replied that he wanted to but didn't think he should since he was ill. I encouraged him to smoke which both made him a little happier and alleviated his dry mouth. Hard, sour candies, chewing gum or ice chips to suck on can also be helpful.

Blurred vision can be very disturbing to patients with advanced terminal disease. Time can become very heavy for the patient who is not able to read due to visual anticholinergic effects. Perhaps the most significant anticholinergic induced problem is urinary retention. Urinary catheterization often results in gram-negative infection in debilitated patients. Management of urinary retention with bethanechol is greatly preferred to catheterization. Constipation is a common problem in many patients and is exacerbated by narcotics. Anticholinergic effects may worsen this problem. Dietary management and cathartics are often necessary.

### Unproven Treatments

There are unsubstantiated claims that marijuana is useful as an analgesic. There is a pharmacological basis for this claim. Marijuana may inhibit prostoglandin synthetase. The degree or clinical usefulness of this effect is unclear.

During the past decade, research into the role that psychedelic agents may play in helping patients to accept their terminal illnesses has been conducted.[44] Hallucinogens have been used as adjuncts to psychotherapy. Results of this work appear similar to results of the hospice approach to terminal disease in which psychedelic agents are not employed. In both approaches open honest communication with the patients and excellent social support are provided. This communication and support appear to be major factors in successful encounters with terminal disease. The use of LSD or other psychedelic drugs in terminal disease is highly questionable.

Dextroamphetamine has been shown to be an effective potentiator of morphine as an analgesic in a single dose study in healthy volunteers.[45] The use of other potent drugs with narcotics requires careful weighing of risks and benefits. The former may outweigh the latter as expressed in a editorial by Vandam.[46]

Vandam Editorial[17]

In recent years there have been undocumented suggestions that Vitamin C therapy of advanced cancer is efficacious. A controlled, double-blind study of 150 patients with advanced cancer which was conducted at the Mayo Clinic failed to show any therapeutic benefit of high dose Vitamin C treatment. Furthermore, patients in the Vitamin C group experienced higher incidences of nausea, vomiting, heartburn, diarrhea, leg swelling and other symptoms than did the patients in the placebo group.

Creagan et al. paper[18]

## Conclusion

Patients with advanced, irreversible disease often have many symptoms that are amenable to drug management. But drugs alone are seldom adequate for good symptom control. Meticulous physical care, psychosocial support and utilization of multiple symptom control modalities are important.

The patients' changing metabolic and excretory capabilities require continual monitoring of drug therapy and adjustment of doses and administration schedules when appropriate. Monitoring can usually be accomplished by noninvasive means through careful observation and documentation. The needs of patients with terminal disease differ from those of patients whose diseases will resolve.

Drug therapy is frequently central to symptom control in patients with advanced, irreversible disease. Skillful use of symptomatic drugs can change an agonizing process of dying to one of successful living for the time that the patient has remaining.

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## APPENDIX

Dr. Lipman has referenced articles previously published throughout the text of his module. Those that copyright permission could be obtained for are included in this section to support his writing. The following list represents all of those that were recommended. It is recommended that the facilitator obtain the references that could not be included to aid in the presentation. The list is in order of reference within the text.

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OCCASIONAL NOTES

## Prof. Wall's Three Phases of Pain

The "gate theory" of pain, proposed in 1965 by Melzack and Wall.[1] envisioned a system of progressive presynaptic modulation of nociceptive impulses that started the moment posterior rootlets delivered their electrical information to sensory neurons in the dorsal horn. The resultant appreciation of the role of the spinal cord in pain mechanisms has boosted development of new therapeutic approaches such as dorsal column stimulation.

Prof. Wall now has contributed another landmark to the better understanding of pain. In the Bonica Lecture,[2] he delineates three sequential stages of pain - immediate, acute, and chronic - each, rather unexpectedly, linked less to injury than to body state. Pain, according to Wall, is more an awareness-of-a-need state (like hunger) than an awareness-of-an-event sensation (like seeing). Though pain can be linked causally to injury, it need not be; injury does not always generate pain, nor does pain always signal injury.

Wall points out that seeing and hearing, sensations related to external events, enable us to describe quite accurately the location, duration, and strength of the external stimulus; whereas hunger and thirst, sensory experiences evoked by internal events, not only are difficult to describe precisely, but also are affected strongly by emotional state. The same is true with pain; often the stimulus is unknown, and the source mis-localized. Pain, though it profoundly affects us, seldom tells us its cause. Assuming all along that pain serves some sort of informative function, what then is its role?

In answer, note that the behavior associated with internal feelings is powerfully influenced by other events. The thirsty man will look for water; the thirstier he is, the more intense the effort and the greater the stress. With pain, too, go emotional responses such as fear, anger, anxiety and concern. These emotional responses are not separate manifestations, they are very much part of the overall pain response. Thus, Wall will have us look to the result of a stimulus rather than to the stimulus itself. Pain emerges as a general reaction pattern comprising three successive, distinct, and natural behavioral phases whose intensity and duration determine the final response.

The immediate first phase of response to injury is directed to protection, to destroy the source of injury or to escape from it; the soldier fights back the enemy or, if badly hurt, hides from him. More often than not, pain does not occur in this initial phase because man calls on other reactions to care for his more immediate urgent needs.

Acute pain sets in when one can concentrate on protecting the wound. When events come fully under one's control, attention can be directed wholly to caring for the injury rather than on what caused it. The acute phase is the transition between coping with the cause of injury and preparing for recovery. It is dominated by pain and by anxiety for past, present and future. Acute anxiety is as much part of this phase as is acute pain.

But what if you hit your thumb while driving a nail? That hurts badly and instantly. Why would a much more serious injury not hurt at all, at first? Evidently, when events are under one's control from the start, the first phase of the pain syndrome is skipped, and the second (acute) phase entered immediately.

The third or chronic phase of pain is marked by recovery from injury, quiet inactivity being Nature's way of providing optimal conditions for healing. The great majority of injured people recover. But in a few patients without permanent injury the chronic phase drags on far beyond the necessity for recovery. It is this extreme of a natural sequence of events that provides the setting for the chronic pain syndrome.

Intractable pain, together with depression and lassitude, characterize the extreme of the chronic phase. Behavior changes, the patient focusing more and more on his condition and less and less on his surroundings. Complaints seem to be unremitting, depression deepens, and the search for treatment begins to dominate life. Since the original signs of injury or disease have resolved long since, here again is a mismatch between amount of pain and amount of injury. And, since we can't find anything wrong organically to match up with the very apparent distress of the patient, chronic pain is all too often relegated to the "it's all in your mind" category.

Pain is not, as we often think, the simple sensory messenger that signals tissue damage. Rather, pain signals a body state like thirst or hunger; pain tells the body to take appropriate action. Just as hunger is associated with the search for food, pain is associated with the search for treatment of injury. Just as there are disorders of hunger such as obesity, so there are disorders of pain such as causalgia. Seeing pain in this new perspective ought to bring us closer to improved or novel means for treating one of man's more unpleasant and disabling afflictions. It will be none too soon.

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Rudolph H. De Jong, M.D.

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# PAIN RELIEF BY INTRATHECALLY APPLIED MORPHINE IN MAN

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In recent animal experiments, opiate receptors were identified autoradiographically in the brain and the substantia gelatinosa of the spinal cord.[1] In a corollary study, morphine administered directly into the spinal subarachnoid space of the rat produced potent analgesia.[2] Subsequent studies confirmed this finding and showed that repeated intrathecal injections of morphine did not cause adverse tissue reactions of the spinal cord.[3] Also, an opiate-like analgesic effect was reported to occur after the injection of methionine$^5$-enkphalin (Met$^5$-enkephalin) and its analogs.[4] The results of these animal experiments prompted us to study the effect of intrathecally applied morphine in eight patients suffering from intractable pain of inoperable cancer.

## METHODS AND MATERIALS

Eight patients who had severe intractable pain in the back and legs secondary to malignancies of the genitourinary tract with invasion of the lumbosacral plexus were selected for study. Systemically administered narcotic analgesics had not suppressed the pain when given at reasonable dose levels and frequencies (5-10 mg every four to six hours), whereas high, clinically effective doses (10-20 mg every two to four hours) were almost always complicated by depression of the central nervous system.

All procedures and possible risks pertaining to this study were explained to the patients, and each signed a written informed-consent form. Systemic narcotics were not given for at least two hours before treatment. Neurologic examinations were performed immediately before and one hour after the morphine injections.

Each patient was shown the visual pain scale (0 to 10) and instructed in its use by a person who was unaware of the pattern of double-blind study. The baseline pain intensity was determined 30 min before intrathecal injection. Patients then received physiologic saline solution intrathecally at the second and third lumbar interspace with or without morphine, 0.5 to 1.0 mg. After administration of the agent, the intensity of pain was assessed at 15 min intervals for one hour. Vital signs were carefully monitored during this hour. When the pain was relieved patients were told to record at hourly intervals, whether relief was still present.

The injections were given in random order, so that neither the patient nor the person evaluating the pain knew which type of agent was used. The intervals between injections ranged from four to 48 hours, depending on the patient's response. Each patient received both saline control and morphine injections. They were repeated as many times as the patient was willing to participate. Totals of 17 injections of morphine and 12 of physiologic saline solution were given.

## RESULTS

Two of the eight patients (Patient 1 and Patient 6) reported complete relief of pain after separate injections of morphine and physiologic saline solution, although the mean duration of relief after morphine injection was 15 hours, whereas that after injection of physiologic saline solution was seven hours (Table 1).

TABLE 1. Clinical Results with Intrathecally Applied Morphine

|  |  |  |  | Pain |  |
|---|---|---|---|---|---|
|  | Age (Years), Sex | Number of Injections | Agent and Dose (mg) | Mean Change in Intensity (Scale of 0 to 10) | Mean Duration of Relief (Hours) |
| Patient 1 | 56, M | 3 | Morphine (0.5) | 7, 1 | 13 |
|  |  | 2 | Saline solution | 6, 1 | 6 |
| Patient 2 | 60, M | 2 | Morphine (0.5) | 7, 1 | 12 |
|  |  | 2 | Saline solution | 8, 8 | No relief |
| Patient 3 | 57, F | 2 | Morphine (0.5) | 5, 0 | 22 |
|  |  | 1 | Saline solution | 6, 5 | No relief |
| Patient 4 | 58, M | 2 | Morphine (1.0) | 5, 0 | 20 |
|  |  | 2 | Saline solution | 5, 4 | No relief |
| Patient 5 | 66, M | 2 | Morphine (0.5) | 5, 1 | 14 |
|  |  | 1 | Saline solution | 6, 7 | No relief |
| Patient 6 | 71, M | 2 | Morphine (0.5) | 3, 1 | 10 |
|  |  | 1 | Saline solution | 3, 1 | 8 |
| Patient 7 | 51, M | 3 | Morphine (1.0) | 4, 0 | 24 |
|  |  | 2 | Saline solution | 5, 4 | No relief |
| Patient 8 | 62, M | 1 | Morphine (0.5) | 4, 0 | 21 |
|  |  | 1 | Saline solution | 5, 5 | No relief |

The intrathecal injection of morphine was accomplished with little discomfort to the patient. Complete relief of pain allowed greater ease in use of the lower extremities. Although patients experienced noticeable enhancement of their feelings of well-being, they showed no sign of sedation, respiratory depression, or other behavioral changes. During the periods of complete pain relief, perception to pinprick and light touch remained intact, as did all other neurologic functions.

## DISCUSSION

The small number of cases studied renders our observations preliminary. Another limitation is that evaluation of methods for controlling pain lacks standardized means for measuring pain.

After abandoning the McGill Pain Questionnaire[5] because of the grossly obvious analgesic effect of intrathecally administered morphine, we settled on the visual pain scale.[6] [7] and found it to be workable, although all it does is quantitate pain intensity. Repeated application of the scale did not seem to affect the rating significantly, for neither patients nor evaluating personnel were familiar with the ramifications of a double-blind study. To try to avoid placebo reactions from doctor-patient interaction, we had the same person administer the morphine and the physiologic saline solution.

Notwithstanding the limitations of this study, we were sufficiently impressed by the results to submit the data for publication in the hope that others will be stimulated to evaluate independently this potential mode of symptomatic therapy for incurable cancer problems. Six of our eight patients were clearly able to distinguish morphine from placebo, did so on repeated occasions, and believed they had obtained satisfactory and relatively long-lasting relief. In none was there any demonstrable evidence of side-effects on the central nervous system. Relief of pain after injections of physiologic saline solution in two of the patients came as no surprise, since as many as 40 per cent of cancer patients may obtain substantial relief of pain from placebo medications.[8]

Although the absence of depression of the central nervous system suggests that intrathecally administered morphine acts on the spinal cord alone--perhaps on the substantia gelatinosa--our study does not exclude an interaction between morphine and receptors in the brain. If narcotics or endogenous opiate-like substances can be repeatedly administered intrathecally, prolonged control of pain by application of a drug reservoir or an indwelling cannula may be possible. The advantage of this method would be to provide predictable relief from pain without attendant loss of motor or sensory function. It is tempting to speculate that this technique may be used for obstetric analgesia or postoperative pain. However, further studies are needed to establish the clinical applicability of intrathecal injections of morphine, especially with regard to the risk to the spinal cord of repeated administration and the effects on tolerance to and dependency on the drug.

The other six patients reported complete relief from pain after the morphine injections. Relief lasted 12 to 24 hours, the average duration being 20 hours. Elapsed times from instillation of the drug to its maximal effect ranged from about 15 to 45 min. Increasing the dose of morphine to 1.0 mg did not prolong the relief proportionately. In contrast to the good response to morphine, there was no improvement after nine injections of physiologic saline solution. The results of repeated injections of either morphine or physiologic saline solution in the same patient were strikingly reproducible. The typical pattern of changes in intensity of pain from three patients, is shown in figure 1.

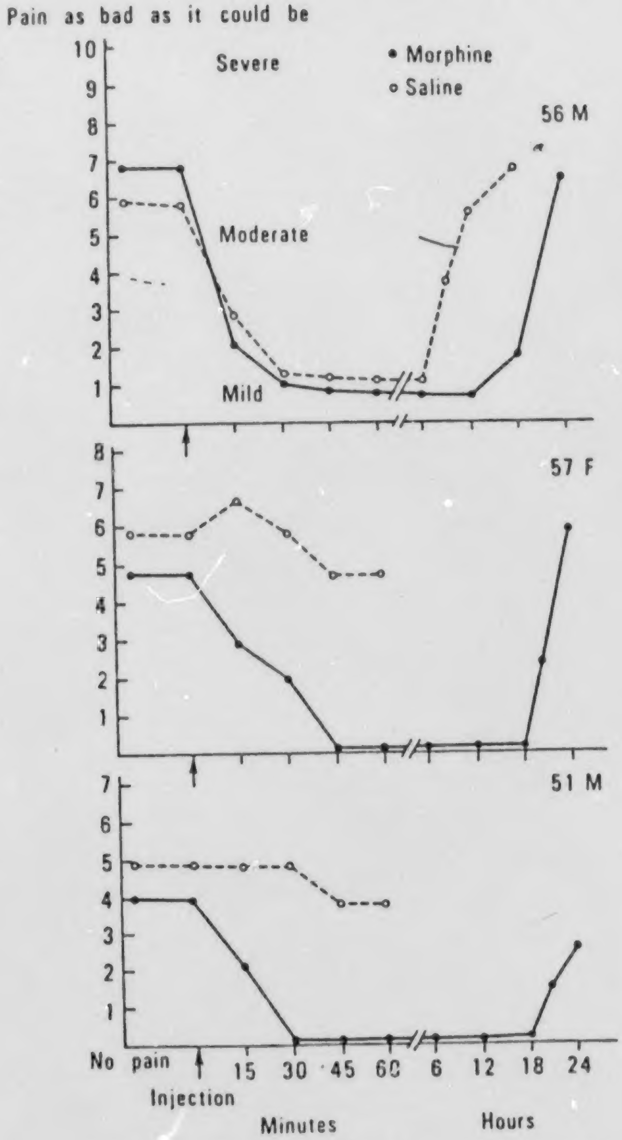

FIG. 1. Changes in intensity of pain after intrathecal injection of physiologic saline solution or morphine.

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From the Department of Drugs, American Medical Association, Chicago

## Should Heroin Be Available to Treat Severe Pain?

THE TREATMENT of patients with chronic, severe pain is a major problem. It has been estimated that 70% to 90% of hospitalized cancer patients suffer severe pain, although specific data on this point are not available.

Because of reports that many cancer patients do not obtain adequate pain relief, the news media have publicized a proposal that heroin should be made available for these patients. This proposal is based on the belief that heroin has certain advantages over morphine and other available strong analgesics. Its proponents claim that it causes more euphoria and less sedation, nausea, and constipation, and it enhances the appetite. However, none of the supposed benefits have been demonstrated by controlled clinical trial.[1] In summarizing a review of the published literature on heroin prior to 1957, Eddy et al[2] stated:

> Most reports agree that nausea and vomiting and the milder side-effects occur less frequently after heroin than after morphine. Its (heroin's) respiratory depressant effect, however, on the basis of quantitative data is at least as great. Most reports agree also that heroin is more addicting than morphine.

In a review of analgesics, including heroin, Lasagna[3] commented:

> With few drugs is there a greater discrepancy between volume of published material and content of convincing and reliable information, than in the case of heroin. . .It is unfortunate that so much emphasis has been placed on papers that are either insufficiently controlled or irrelevant.

### RESULTS IN INVESTIGATIONAL STUDIES

In one well-controlled study, the effects of morphine, heroin, and a saline placebo (administered subcutaenously) on subjective responses were compared in healthy male volunteers, "postaddicts," and chronically ill patients; there was a notable similarity in the responses produced by the two drugs. The principal differences were that a majority of the postaddicts considered morphine to be more pleasant than heroin and that the healthy volunteers experienced a greater degree of dysphoria with morphine. Lasagna et al[4] concluded, "The results with heroin did not justify its reputation as a great stimulant or as a producer of intense euphoria."

In another study it was reported that addicted subjects could not distinguish between the effects of the two drugs accurately after subcutaneous administration.[5] In additional comparative studies of the subjective and objective effects in healthy volunteers,[6,7] a pattern of similarity of effects was found when the two drugs were given in equianalgesic doses; the only difference, if any, was that the effects of heroin were judged to be less pleasant than those of morphine. Since addicts prefer to inject drugs intravenously, morphine and heroin were compared in postaddicts by this route of administration.[8] It was found that the subjects "did not report so-called desirable symptoms, such as 'euphoria' more frequently for heroin than for morphine....The overall pattern of opiate symptoms and signs were similar for the two drugs." The authors concluded:

> This work does not support the claim that addicts find heroin markedly superior to morphine....Several lines of evidence (time course, similarity of effects, metabolic fate) indicate that heroin and morphine have essentially similar actions except for potency (heroin was found to be two to three times more potent on a milligram basis than morphine) and absorption rate, and strongly protest the claims that heroin is superior to morphine clinically.

## RESULTS IN CLINICAL STUDIES

Although the number of studies comparing morphine and heroin in various clinical uses, e.g., coronary, postoperative pain, preanesthetic medical is limited,[9-11] the results have not demonstrated that heroin has any advantages over morphine. Since it has been claimed that an advantage of heroin is that it causes a lower incidence of side effects, it is notable that Dundee et al[11] concluded:

> Our findings do not point to a definite superiority of diamorphine (heroin) over morphine with respect to emetic and other side effects nor was there any obvious euphoriant action....In general, we would support the view of Lasagna... that "heroin seems little better or worse than morphine in its capacity to produce analgesia, respiratory depression and other side effects, or in addiction potential."

Twycross[1] pointed out that several possible complicating factors, e.g., stability of aqueous solution of heroin, potency ratio, oral activity and fate, effect of the mobility of patients on side effects, and sex differences, had not been adequately considered by many previous workers and noted that "the need for a scientifically conducted trial comparing diamorphine (heroin) and morphine in patients with advanced malignant disease is apparent." The results of such a clinical trial conducted by this investigator, in which several of the factors cited were considered, are, therefore, important.[12]

In a double-blind study of about 700 terminally ill cancer patients, the effects of equianalgesic doses of heroin and morphine on pain, mood, sleep and appetite, as well as their propensity to cause nausea, vomiting and constipation, were compared. Each analgesic drug was administered in an elixir containing cocaine hydrochloride (10 mg/dose); a phenothiazine was also given as an antiemetic, and other drugs were prescribed when indicated clinically. In 146 patients, it was possible to cross over from one medication to the other after about two weeks. In the female crossover patients, no difference was noted in either pain or other symptoms evaluated; however, the male crossover patients experienced more pain and were more depressed while receiving heroin. The author suggested that the potency ratio may be different for the men, and, if this is allowed for, the difference in mood is probably not meaningful.

On the basis of the results of this study, it was concluded that there is no difference between heroin and morphine administered orally with cocaine and a phenothiazine every four hours at individually determined doses; thus, morphine is a satisfactory substitute for orally administered heroin in this combination of drugs commonly designated Brompton's mixture. The use of a modified Brompton's mixture containing morphine is under study in this country.

With regard to the results of these various studies cited, it is noteworthy that an expert Ad Hoc Panel for the White House Conference on Narcotic and Drug Abuse stated in 1962: "There is a widespread misconception that heroin has effects significantly different from those of morphine. It does not, and this misconception should be dispelled permanently."[13] None of the studies conducted since 1962 have provided any evidence to alter that conclusion.

Despite the consensus of expert opinion and preponderance of evidence from results of scientific studies that have failed to demonstrate any advantage of heroin over morphine, certain groups have continued to propose that heroin be reclassified as a Schedule II drug under the Controlled Substances Act; this would permit physicians to prescribe the drug to alleviate severe pain in patients with cancer. Despite this evidence, extensive research programs on heroin have been initiated by the National Institute on Drug Abuse to study again the effects of heroin on cancer patients. Although the number of well-controlled studies of heroin in cancer patients is limited, there is no reason to expect that the results in the newer programs will differ from those reported in earlier studies.

## APPROPRIATE USE OF ANALGESICS

One reason many patients do not recieve optimum therapy for relief of pain is due to misprescribing of analgesics. Results of one study on narcotic use in two hospitals showed that 32% of patients remained in severe distress,and 41% of patients remained in moderate distress, despite the administration of narcotic.[14] It was determined that the physicians underestimated the dosage requirements and overestimated the duration of action of the narcotic. Furthermore, because they had misconceptions concerning the danger of addiction, they were reluctant to order an increase in dosage or in frequency of administration even for patients with severe pain caused by a terminal malignant disease.

In the introduction of a recently published symposium on pain, one of the major reasons for the deficiency in treating patients with chronic pain was stated to be "the improper of inadequate application of knowledge currently available to care for these patients. The reasons for this include the lack of organized teaching of medical students and physicians in the treatment of patients with chronic pain."[15]

The available analgesics, when properly used and in combination with other agents when indicated, can be effective; however, their use in chronic pain differs in certain respects from their use in acute pain. Whereas some adverse reactions and the development of tolerance to the analgesic effect may be relatively more important in chronic pain, the problem of iatrogenic addiction is not as important as relief of pain in patients with terminal illness. Since patients may react differently to one drug than to another, the selection of drugs and dosage regimen must be individualized. The common practice of prescribing analgesics as needed (prn) should be changed to a regular, time administration for these patients to prevent the recurrence of pain. Providing comfort to the patient should be the primary objective of treatment.

## CONCLUSION

Inasmuch as the available scientific evidence indicates that heroin has no advantage over morphine, changing its classification under the Controlled Substances Act to make it available as a Schedule II drug would not provide physicians with a more effective analgesic, but it would increase the problems of its control. Rather, patient care could be improved through a greater emphasis on the education of physicians in the treatment of patients with chronic pain problems.

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# THE BROMPTON MIXTURE VERSUS MORPHINE SOLUTION GIVEN ORALLY: EFFECTS ON PAIN

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The Brompton mixture is widely used as an effective method for controlling pain in cancer patients. In a double-blind crossover trial a standard Brompton mixture containing morphine, cocaine, ethyl alcohol, syrup BP and chloroform water was compared with morphine alone in a flavoured aqueous solution; both were administered orally. Pain was measured by means of the pain intensity index of the McGill Pain Questionnaire. Ratings of confusion, nausea and drowsiness were obtained from both the patients and their nurses and relatives. The data showed that there was no significant difference between the Brompton mixture and morphine administered orally for any of the variables. Both relieved pain effectively in about 85% of the patients.

The effectiveness of the Brompton mixture for the control of pain in cancer patients has been demonstrated.[1,2] A typical standard Brompton mixture contains a variable amount of morphine, 10 mg of cocaine, 2.5 mL of 98% ethyl alcohol, 5 mL of syrup BP and a variable amount of chloroform water. Morphine has well known analgesic properties, and its sites of action are becoming better understood.[3] The contribution of the other ingredients, however, are less clearly documented. Cocaine is known to be absorbed after oral ingestion,[4] but it is not known to have general analgesic properties; morover, it produces a "high" when administered in doses in the range of 2 mg/kg,[4] which is much greater than the 10 mg in each dose of the Brompton mixture. The role of chloroform water has not been determined, and while ethyl alcohol reduces the rate of degradation of diamorphine (heroin)[5] its function in a mixture containing morphine has yet to be investigated.

The complexity involved in dispensing the standard Brompton mixture, the restricted availability of cocaine in many countries (particularly the United States), and the possibility that irritation and pain may be produced by the small amount of ethyl alcohol in the mixture[6] suggested the desirability of comparing a standard Brompton mixture with a simple aqueous morphine solution for the control of pain.

## PATIENTS AND METHODS

### Patients

The subjects were 44 patients who had intractable pain due to advanced malignant disease. All had sufficiently severe pain, in the judgement of the treating physician, to warrant the use of narcotic analgesics. The patients were associated with several services of the Royal Victoria Hospital: the outpatient day-care service of the oncology department, the private and public wards, and the palliative care service,[7] both in the hospital and at home.

## The analgesic mixtures

The Brompton mixture that was prescribed to the patients contained a variable amount of morphine, 10 mg of cocaine, 2.5 mL of 98% ethyl alcohol, 5 mL of syrup BP and enough chloroform water to make a total volume of 20 mL. The morphine solution consisted of a variable amount of morphine, 5 mL of syrup BP, 3 mL of essence of orange flavouring, and enough distilled water to make a total volume of 20 mL. The two solutions were coloured with three drops of egg yolk yellow so that the final solutions were identical in colour and consistency, and could not be distinguished on the basis of these features by the patients, nurses or physicians. A phenothiazine (prochlorperazine in doses of 5 to 10 mg) was prescribed in most patients to counteract the nausea induced by the initiation of narcotic therapy.

## Pain ratings

Pain ratings were obtained by means of the present pain intensity index of the McGill Pain Questionnaire,[8] which has been found to provide a valid, reliable measure of pain.[2,9] Pain was rated on a scale of 0 to 5 as follows: 0 = none; 1 = mild; 2 = discomforting; 3 = distressing; 4 = horrible; and 5 = excruciating. The list of descriptions of pain was read to the patient, who was asked to choose the word that best characterized his or her pain at the moment. The procedure was completed in 1 to 2 minutes.

## Ratings of confusion, nausea and drowsiness

Ratings of confusion, nausea and drowsiness were obtained by means of questions to the patient that were based on the following set of descriptions, which was read to him or her. Confusion was rated as: 0 = none; 1 = mild (occasional); 2 = moderate (frequent, but there are periods of lucidity); and 3 = severe (continual). Nausea was rated as: 0 = none; 1 = mild (patient aware of nausea, but it is not interfering with eating); 2 = moderate (interferes with eating); and 3 = severe (continual). Drowsiness was rated as: 0 = none (patient alert); 1 = mild (patient drowsy on occasion but easily roused); 2 = moderate (patient often drowsy but easily roused); 3 = severe (patient often somnolent and roused with difficulty). This procedure took about 3 to 10 minutes.

Both English and French versions of all questions were available so that the questions could be asked in the patient's mother tongue. Of all interviews 75% were conducted in English and 25% in French.

## Experimental design

A double-blind crossover trial was designed in which patients received either the Brompton mixture or the morphine solution for about 2 weeks and were then given the other mixture. The Gellerman randomized table[10] was used to ensure an equal number of patients in the two orders of presentation. Although all staff members were aware of the nature of the trial, they did not know when the cross over occured, and none remarked on differences between the two preparations before the ratings were obtained. Six patients commented on a difference in taste - three when changed from the Brompton mixture to the morphine solution, and three when changed in the other direction - but all continued to take the new preparation.

When the hospital pharmacy received a prescription for the Brompton mixture the pharmacist consulted the random allocation table and dispensed the appropriate preparation for the patient. The interviewer (J.M.G.) was then informed that a patient had received a narcotic solution but was not told which preparation it was. Four to 7 days after the patient had begun taking the preparation the interviewer introduced himself to the patient (in person at the hospital or over the telephone to the patient at home) and told the patient that the effectiveness of the pain medication was being assessed, and that a few questions would be asked.

The interviewer then asked the patient for a rating of his or her pain using the pain intensity index, and questions were asked to rate confusion, nausea and drowsiness. Two more pain ratings were obtained, usually on the 2 following days. During this period the patient's nurse and a relative who was familiar with the patient's day-to-day condition were asked to rate the patient's pain, confusion, nausea and drowsiness.

After the ratings were completed for the first preparation the interviewer informed the pharmacy. When the patient needed a renewal of the prescription, the pharmacist dispensed the other preparation. The ratings for pain and other variables were subsequently obtained in the same way and at the same time intervals. Interviews were conducted at random times following the dispensing of medication.[2]

Thus, three pain ratings were obtained from each patient for each mixture, and a single rating was obtained for each of the remaining three variables from the patient, a nurse and a relative. The decision to obtain a single rating for confusion, nausea and drowsiness was dictated by the desire to disturb the patient as little as possible. Furthermore, the pain rating was based on pain felt at the precise time the question was asked, while the answers for the other three variables were based on evaluations over a longer period.

Nurses or relatives who thought they could not answer the questions because of insufficient time spent with the patient were not pressed to do so, and some patients had no regular contact with nurses or relatives. Therefore, the number of answers by nurses or relatives was less than the number of patients in each group.

When each patient had completed participation in the trial - that is, had received both preparations and had been interviewed six times - the pharmacist continued to dispense the second preparation for all subsequent prescriptions.

The trial was terminated when 30 patients had completed participation. The pharmacy logbook was then obtained and the patients' data were tabulated and evaluated statistically with use of the correlated _t_-test for the

Table I—Effects of Brompton mixture and morphine solution given orally on pain, confusion, nausea and drowsiness

| Study design | Mean dose (mg) of morphine | Mean rating* | | | |
|---|---|---|---|---|---|
| | | Pain | Confusion | Nausea | Drowsiness |
| Crossover | | | | | |
| Group 1 (n = 20) | | | | | |
| Brompton mixture | 26.8 | 1.8 | 0.1 | 0.8 | 1.0 |
| Morphine solution | 24.5 | 1.7 | 0.1 | 0.3 | 1.1 |
| P value | 0.19 | 0.75 | 1.0 | 0.06 | 0.70 |
| Group 2 (n = 7) | | | | | |
| Brompton mixture | 18.0 | 1.6 | 0.1 | 0 | 0.7 |
| Morphine solution | 21.4 | 1.6 | 0.1 | 0 | 1.4 |
| P value | 0.67 | 0.93 | 1.0 | 1.0 | 0.05 |
| Independent sample | | | | | |
| Brompton mixture (n = 11) | 21.4 | 1.9 | 0.2 | 0.5 | 1.2 |
| Morphine solution (n = 6) | 15.8 | 1.9 | 0.2 | 0.7 | 1.3 |
| P value | 0.39 | 0.92 | 0.94 | 0.65 | 0.77 |

*See text for explanation of scoring systems.

crossover design, the standard t-test for independent samples and the chi-square test for 2 x 3 analyses. A P value of 0.01 was chosen as the criterion for statistical significance.

## RESULTS

### Effects of the two preparations

Tabulation of the data revealed that of the 30 patients who had completed the two series of the trial 20 had done so in the same environment. This is an important consideration because the effectiveness of the Brompton mixture is influenced by environmental factors.[2] Therefore, this group - group 1 in Table 1 - provided most of the information in this study. Of the 20 patients 11 had received the Brompton mixture and then the morphine solution, while 9 had received the preparations in the reverse order. During the trial 8 of the 20 patients lived at home but had frequent visits from nurses of the palliative care service, 8 were in hospital (in private rooms, public ward rooms or the palliative care unit) and 4 lived at home under supervision of the day-care service of the oncology department.

The data showed that the mean amount of morphine per dose was similar for the two preparations. The mean pain ratings in group 1 during use of the Brompton and morphine preparations were 1.8 and 1.7 respectively; this difference was not significant. The data, therefore, suggest that the predominant analgesic effect of the Brompton mixture is due to the morphine it contains. Furthermore, the mean scores for confusion, nausea and drowsiness were extremely low in both series, and there were no significant differences. Thus, there is no evidence to suggest that the cocaine, ethyl alcohol or chloroform water had any significant effect on confusion, nausea or drowsiness. It is, of course, possible that the additional ingredients had an effect that was too subtle to be detected by our rating procedures. If so, however, the effect may be considered too small to have had any clinical significance.

A subject group of 20 is substantial in a crossover design, and the minor differences were so small as to suggest that even if the sample had been several times larger there would still have been no significant differences detectable.

Additional data obtained in this study permitted further comparisons, the results of which reinforced the conclusions drawn from the main group of patients.

The study of a group of seven patients - group 2 in Table I - may be considered a replication of the main study. In this group the first narcotic preparation was given in one of several environments (such as a private hospital room or at home), but the second was given while the patient was under supervision of the palliative care service either in hospital or at home. Since three patients were given the Brompton mixture and then the morphine solution and four were given the preparations in the reverse order, the effects of environment may be considered to be cancelled out. The data for group 2 were very similar to those for group 1, and no significant differences could be found.

Finally, 17 patients received either the Brompton mixture or the morphine solution but did not receive the other preparation because their physical condition deteriorated during the study so that they were too ill to answer questions, or because they died or were transferred to other facilities before or during administration of the second preparation. These patients were treated as two independent samples of 11 and 6 patients receiving the Brompton mixture and the morphine solution respectively. The data showed a striking similarity to those of group 1, and there were no significant differences between the two small groups for any of the measures.

Taken together, then, the data from these groups represent strong evidence supporting the hypothesis that morphine is the main active ingredient of the Brompton mixture and there is no evidence that the other ingredients enhance or otherwise modify the effects of the morphine.

A more discrete analysis of the data revealed the nature of the effects of the Brompton mixture and the morphine solution. The mean ratings for each patient were categorized into three groups - 0 to 1.9, 2.0 to 2.9, and 3.0 to 5.0 - that may be considered as representing mild, moderate and severe pain, respectively. Although the data showed some variation among the three groups, there was good agreement on the whole (Table II). In approximately 85% of the patients, pain was mild or moderate on the average, and such pain is considered by most people to be bearable. The Brompton mixture and the morphine solution were ineffective - that is, pain was severe - in about 15% of the patients.

The final analysis compared the effects of the Brompton mixture and the morphine solution on confusion, nausea and drowsiness, with ratings by patients, nurses and relatives at three levels: mild (0 to 1), moderate (2),

Table II—Percentages of patients with mean pain ratings within specific ranges

| Study design and rating range | % of group |  |
|---|---|---|
|  | Brompton mixture | Morphine solution |
| Crossover |  |  |
| Group 1 |  |  |
| 0-1.9 | 65 | 45 |
| 2.0-2.9 | 20 | 40 |
| 3.0-5.0 | 15 | 15 |
| Group 2 |  |  |
| 0-1.9 | 57 | 71 |
| 2.0-2.9 | 43 | 14 |
| 3.0-5.0 | 0 | 14 |
| Independent sample |  |  |
| 0-1.9 | 45 | 50 |
| 2.0-2.9 | 45 | 33 |
| 3.0-5.0 | 9 | 17 |

and severe (3). The data showed no significant differences between the preparations, and there was excellent agreement among the ratings of the patients, nurses and relatives (Table III).

It may be concluded, then, that the Brompton mixture and the morphine solution are associated primarily with low levels of pain, confusion, nausea and drowsiness, and that there is no difference between the preparations for any of these variables.

## Pharmaceutical observations

After a shelf period of about 1 week the morphine solution began to cloud. Analysis revealed that the solution contained yeast, fungi and bacteria. Such contamination has not been an observed problem with the Brompton mixture even after a shelf period of 4 weeks or more. The morphine solution with the syrup BP, therefore, appears to be an excellent culture medium. Gross contamination has subsequently been eliminated for a shelf-life of at least 3 weeks by the addition of 1.5 mL of 98% ethyl alcohol per 20-mL dose.

Table III—Percentages of ratings for confusion, nausea and drowsiness in mild (0-1), moderate (2) and severe (3) categories, as judged by patients, nurses and relatives

|  | % of ratings |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  | Patient |  |  | Nurse |  |  | Relative |  |  |
| Variable | 0-1 | 2 | 3 | 0-1 | 2 | 3 | 0-1 | 2 | 3 |
| Confusion |  |  |  |  |  |  |  |  |  |
| Brompton mixture | 100 | 0 | 0 | 93 | 7 | 0 | 100 | 0 | 0 |
| Morphine solution | 100 | 0 | 0 | 85 | 15 | 0 | 100 | 0 | 0 |
| Nausea |  |  |  |  |  |  |  |  |  |
| Brompton mixture | 75 | 15 | 10 | 80 | 7 | 13 | 78 | 14 | 7 |
| Morphine solution | 95 | 0 | 5 | 100 | 0 | 0 | 92 | 0 | 8 |
| Drowsiness |  |  |  |  |  |  |  |  |  |
| Brompton mixture | 63 | 26 | 11 | 80 | 20 | 0 | 65 | 29 | 7 |
| Morphine solution | 65 | 30 | 5 | 77 | 23 | 0 | 69 | 31 | 0 |

## Effect of phenothiazine ingestion

It is normally recommended that a phenothiazine be administered with the Brompton mixture, primarily to counteract the nausea induced by the initiation of narcotic therapy. Prochlorperazine, in doses of 5 to 10 mg, is a potent antiemetic that may potentiate the analgesic properties of the Brompton mixture. In this study prochlorperazine was administered to most patients. The numbers who received it while taking the Brompton mixture and the morphine solution respectively were as follows: 11 and 13 in crossover design group 1; 4 and 5 in crossover design group 2; and 7 and 5 in the independent sample. Since the patients usually took the phenothiazine with each of the narcotic preparations its presence or absence cannot have influenced the results of this study.

## DISCUSSION

The levels of analgesia produced by the Brompton mixture and the morphine solution in this study were comparable to those observed in our earlier study.[2] The effectiveness of narcotics administered orally is influenced by psychologic factors related to the environment in which they are administered. The Brompton mixture, for example, is more effective when taken by patients in the palliative care unit than when taken by patients in private hospital rooms. We had assumed that this was due to the psychologically comforting and supportive atmosphere of the unit, as well as the fact that the mixture was administered every 4 hours without fail in the palliative care unit, while the regimen was not adhered to as strictly in other areas of the hospital. Since most patients in the present study lived at home and may not have taken the narcotic preparation in the exact manner prescribed, it is reasonable to expect pain ratings in this study to be comparable to those obtained when the strict regimen was not followed. Indeed, the pain ratings at the three levels (mild, moderate and severe) in this study were almost identical to those obtained in the first half of our earlier study, before it was impressed on the nursing staff how important it was to administer the mixture at regular 4-hour intervals.

The current results have shown unequivocally that the standard Brompton mixture and a morphine solution produce comparable levels of anagesia. Furthermore, there are no differences between the two mixtures with respect to levels of confusion, nausea and drowsiness. The similarity of the ratings for all measures has indicated that if any differences exist they are not statistically significant. Certainly the differences in our data were so small that they did not have any clinical significance.

The role of the ethyl alcohol in the Brompton mixture was made evident by the appearance of yeasts, fungi and bacteria when it was omitted. The addition of 1.5 ml of 98% alcohol per 20 ml dose suppressed this growth, to allow an effective shelf-life of at least 3 weeks.

These findings indicate, therefore, that simplifying the traditional Brompton mixture by deleting the cocaine and chloroform water and reducing the amount of alcohol, is possible without compromising its effectiveness. Such a step has led to a substantial savings in the time and cost of dispensing the mixture at our pharmacy.

At our hospital we use the name "elixir of morphine" for the morphine solution to be taken orally. Standard concentrations available in our pharmacy are 1, 2 and 5 mg of morphine per millilitre, which allows precise titration of dose to the patient's requirements,[11] with the use of convenient volumes. Flavouring and coulouring substances (such as essence of orange and egg yolk yellow) may be added at the discretion of the physician and pharmacist.

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# CLINICAL EXPERIENCE WITH DIAMORPHINE IN ADVANCED MALIGNANT DISEASE

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Each year, more than four hundred patients with advanced cancer are treated with diamorphine at St. Christopher's. It is administered regularly every four hours in order to achieve and maintain pain relief. Other drugs are prescribed when indicated. In order to answer some of the many questions concerning the use of diamorphine in this way, it was decided to review 500 patients admitted consecutively with advanced malignant disease. It was concluded that:

1. Although, on account of increasing debility, most patients received parenteral treatment during the last 12-48 hours, the majority can be maintained on orally administered diamorphine prior to this time.

2. There is no single optimal dose or maximum effective dose of diamorphine.

3. The prescription of diamorphine does not, by itself, lead to impairment of mental faculties.

4. Tolerance is not a practical problem.

5. Psychological dependence does not occur.

6. Physical dependence may develop, but appears not to prevent the downward adjustments of the dose of diamorphine when considered clinically feasible.

## INTRODUCTION

St. Christopher's Hospice is a medical foundation for those in need of hospital care on account of advanced malignant disease. About 500 patients are admitted each year and, through an outpatient and domiciliary service, an equal number are supported at home. More than 80% of the inpatients receive diamorphine at some time. Usually it is prescribed for severe pain; occasionally, for distressing cough or dyspnoea due to the malignant process or for general discomfort when other measures have failed. About 15% of the patients prescribed diamorphine receive it either predominantly or exclusively by injection, the rest receive it by mouth in an elixir containing both diamorphine and cocaine.[1] It is administered regularly every four hours in order to achieve and maintain pain relief. The initial dose of diamorphine is usually 2.5-10 mg; this is adjusted as necessary until effective analgesia is obtained. The dose of cocaine, however, is not altered. With the aid of a night sedative many patients do not require a dose at 1 a.m. though, if necessary, the patient is wakened to have further medication rather than allow him to wake up later complaining of pain. Ultimately, most patients are transferred to parenterally administered diamorphine for the last 12-48 hours on account of increasing debility; the dose given is half the previous satisfactory oral one.

Virtually all patients receiving diamorphine also receive a phenothiazine, for example, prochlorperazine, promazine, or chlorpromazine, primarily to control or prevent nausea and vomiting but also for sedation and analgesic potentiation. Other drugs, such as glucocorticosteroids, tranquilizers and antidepressants are also prescribed when indicated.

## REVIEW OF 500 PATIENTS

In order to answer some of the many questions surrounding the use of diamorphine in this way, it was decided to review 500 patients admitted consecutively with advanced malignant disease. 282 (56%) were women, 218 (44%) were men. Median survival for the women was twenty days, for the men, twelve. The age distribution is shown in Table 1. Their diagnoses covered the whole range of malignant disease with carcinoma of the breast and of the bronchus accounting for nearly 40% of the total. 418 (84%) received diamorphine for varying lengths of time.

In order to obtain a general impression of the quantities used a maximum dose histogram was constructed (Figure 1). From it we see that over 60% of these patients were maintained on 10 mg/dose or less and only 8% required more than 30 mg/dose. Unfortunately, these figures take no account either of the route of administration or the duration of treatment. As, however, the maximum oral dose used was 40 mg, all the patients represented in the more than 40 mg/dose column received such doses by injection - eleven patients requiring 50 or 60 mg and three 90 mg - and some six to ten patients represented in the other columns also received their maximum dose by injection. The time factor was introduced, initially, by dividing the patients into short and long-term survivors (up to two weeks and more than two weeks) and also into low and high dose groups (up to 10 mg and more than 10 mg).

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[1]

| | |
|---|---|
| Diamorphine Hydrochloride | 2.5 mg or more |
| Cocaine Hydrochloride | 10 mg |
| Ethyl Alcohol 95% B.P. | 2.5 ml |
| Syrup (66% Sucrose in water W/V) | 5.0 ml |
| Chloroform Water to | 20.0 ml |

Presented at the 5th International Symposium on Clinical Pharmacology "Analgesia in Terminal Cancer", Athens, Sept. 11, 1973.

| Age in years | Number of patients |
|---|---|
| < 30 | 5 |
| 30–39 | 14 |
| 40–49 | 40 |
| 50–59 | 118 |
| 60–69 | 174 |
| 70–79 | 117 |
| > 80 | 32 |
| Total | 500 |

Table 1. Age distribution of the 500 patients.

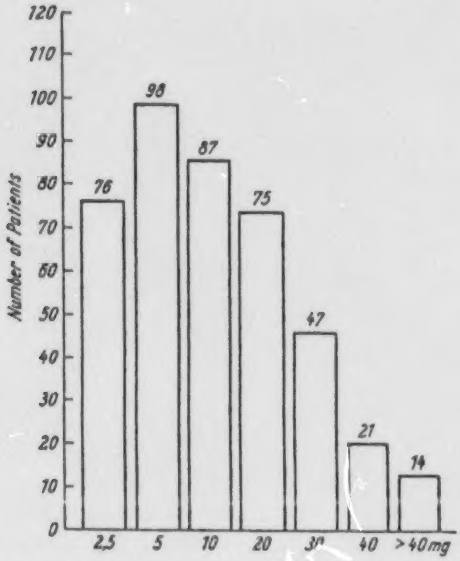


Figure 1. Histogram of maximum doses of Diamorphine.

Significantly more of the short-term survivors required only low doses of diamorphine whereas significantly more of the long-term survivors required high doses (Table 2). It seems, therefore, that the amount of diamorphine required to control a patient's pain increases with time.

In order to examine the rate of increase in dose of diamorphine, the patients were grouped according to survival, excluding the 213 who died within a week of commencing treatment (Table 3). The final daily dose was recorded for each patient: this was defined as the median daily dose given during the last four weeks of treatment in group 5, the last complete week of treatment in groups 3 and 4 and the last three days of the last complete week in treatment in groups 1 and 2. The median final daily dose

| | Number of patients in each group | | |
|---|---|---|---|
| Dose | ≤ 2 weeks | > 2 weeks | Total |
| low<br>(≤ 10 mg) | 194 | 67 | 261 |
| high<br>(> 10 mg) | 43 | 114 | 157 |
| Total | 237 | 181 | 418 |

$\chi^2 = 88$ ($v = 1$)

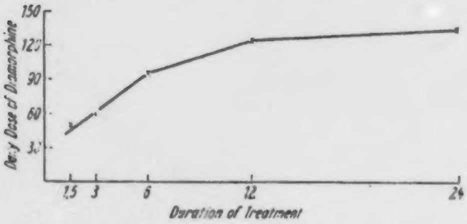
$p < .001$

Table 2. The maximum dose of diamorphine related to duration of treatment.

| Number of complete weeks | 1 | 2–3 | 4–7 | 8–15 | ≥ 16 |
|---|---|---|---|---|---|
| Number of patients | 58 | 39 | 53 | 34 | 21 |
| Median final Daily dose (mg) | 50 | 60 | 95 | 125 | 135 |
| Median duration of treatment (weeks) | 1.5 | 3 | 6 | 12 | 24 |
| Dose/Time | 33 | 20 | 16 | 10 | 6 |

Note: The figures in the bottom row are obtained by dividing the group median final daily dose in mg by the group median duration of treatment in weeks

Table 3. Assessment of the rate of increase in dose of diamorphine in 205 patients who received regular diamorphine for one week or more.



for each gorup was then determined and, in order to correct for time, divided by the group median duration of treatment. An alternative presentation is given in Figure 2. Where the two variables are plotted against each other graphically. There seems little doubt that the rate of increase in dose becomes progressively less the longer the duration of treatment.

It was decided next to examine in detail those patients who survived six months after beginning treatment with diamorphine (Table 4 and 5). None of the patients required a steady, relentless increase in dose. In two cases the graph was like a plateau (Figure 4, 12); in three "crescendo-diminuendo" (Figure 10, 14, 15), and undulating in three more (Figure 3, 5, 9). In the remaining five patients, the pattern was one of multiple plateau separated by steps but in only one of these (Figure 11) were all the steps in an upward direction. How far do these case histories go to answering the question: does the diamorphine have to be increased because of tolerance or because of increasing pain?

| Case No. | Sex | Age | Primary site of carcinoma | Duration of treatment with diamorphine(weeks) | Initial clinical condition | Subsequent course of events |
|---|---|---|---|---|---|---|
| 1 | F | 64 | Breast | 99 | Bedfast, nauseated and anorexic, weight loss, severe pain in back and right leg | Nausea and pain gradually controlled, appetite returned to normal. Fully mobile after two months. Subsequently discharged but readmitted several times on account of pain and/or depression. Inpatient for last ten weeks: mood variable during this time. Diamorphine administered parenterally for last five weeks due to a recurrence of pain |
| 2 | M | 65 | Lung* | 76 | Activity extremely limited by exertional dyspnoea. Also troubled by pleuritic pain. Worried and anxious; poor appetite | Initial treatment included diamorphine, prednisone and antibiotics. He steadily improved, became pain-free and began to occupy himself doing carpentry. Was discharged after six months but subsequently admitted to another hospital for reinvestigation, where the diamorphine was rapidly tailed off. However, owing to withdrawal symptoms this was restarted. The patient died from an acute respiratory infection five months later |
| 3 | F | 62 | Breast | 50 | In pain, nausea, some vomiting. Subsequent worsening of pain. Able to walk with crutches | Became fully mobile, despite pain from fresh metastatic activity. Eventually able to go home for over three months. Finally readmitted with pneumonia and died within hours |
| 4 | F | 47 | Caecum | 46 | Distress, tearful, in pain, vomiting | Improved as symptoms controlled. Troubled by recurrence of pain. Became depressed after about five months. Responded to imipramine. Readmitted four weeks before death. Required parenteral diamorphine to control pain |
| 5 | F | 44 | Breast | 43 | Frightened. Complaining of nausea and vomiting, intermittent pain. Bedfast, paraplegic | Pain, nausea and vomiting brought under control. Mood variable – had major family problems. Latterly drowsy most of the time. Slept for long periods. Died peacefully of pneumonia |

| Case No. | Sex | Age | Primary site of carcinoma | Duration of treatment with diamorphine(weeks) | Initial clinical condition | Subsequent course of events |
|---|---|---|---|---|---|---|
| 6 | F | 71 | Breast | 43 | Too weak to walk. Severe pain developed one week after admission and led to prescription of diamorphine | Gradually improved. Able to walk with frame. Diamorphine stopped for three weeks. Patient discharged twice – for four months on the second occasion. Readmitted due to bad back pain – diamorphine increased. Subsequently steady till death two months later |
| 7 | M | 62 | Lung | 35 | Severe abdominal pain, anorexia, malaise. Occasional nausea and vomiting. Recent marked deterioration with massive hepatomegaly | Pain and vomiting slowly controlled. Became fully mobile and felt generally better. Discharged after six weeks and, apart from a period of two weeks, remained at home until two days before his death over six months later |
| 8 | M | 70 | Prostate | 28 | Depressed by constant pain in thoracic spine, pelvis and other bones. Complained of insomnia, anorexia and weight loss. Able to walk a little. | Became free of pain, fully mobile, ate and slept normally. Felt exceptionally well. Discharged after seven weeks. At home for $4^{1}/_{2}$ months, gradually weakening latterly. Readmitted and died after one week |
| 9 | F | 75 | Rectum | 27 | In severe pain, limited to bed and chair | Cancer pain controlled, arthritic pain alleviated. Gradually mobilised. Discharged after two months to care of a friend. Readmitted after only five weeks as strain too much for friend. She died three months later |
| 10 | F | 69 | Stomach | 24 | Able to walk. Tense and anxious, in severe epigastric and back pain. Complained of nausea, marked anorexia, weight lose. | Became completely free of pain, appetite restored. Fully mobile and able to help on the ward. Discharged three weeks after beginning diamorphine. Able to stay at home for five months. Deteriorated latterly, readmitted and died of pneumonia three days later |
| 11 | F | 64 | Ovary | 24 | Although weak and tired, able to walk a little. In severe epigastric and back pain. Complained of anorexia, nausea and vomiting | Pain controlled adequately though required diamorphine by injection after about five weeks. Vomiting controlled though required changes in treatment. Never became fully mobile. Variable degree of alertness and activity: cheerful when alert |

| Case No. | Sex | Age | Primary site of carcinoma | Duration of treatment with diamorphine(weeks) | Initial clinical condition | Subsequent course of events |
|---|---|---|---|---|---|---|
| 12 | F | 56 | Breast | 24 | Bedfast; in severe pain in both thighs, hips and left pelvis. Nausea, anorexia. Paranoid and depressed | Fully mobile and pain-free. Psychiatric state required constant surveillance. Diamorphine eventually discontinued and patient discharged for five months. Terminal phase probably precipitated by cessation of prednisone: fairly rapid deterioration over several weeks with evidence of renewed secondary activity |
| 13 | F | 16 | Osteo sarcoma | 15 | Severe pain left groin and calf. Discharging biopsy wound. Marked anorexia and nausea. Incontinent of urine, very frightened, withdrawn | Required increasing doses of diamorphine as mobilised. Eventually tailed off in view of remission. A limp due to left leg shortening only residium. Alive and well three years later |

* Later rediagnosed as "pulmonary shadowing of unknown cause"

Table 4. Summarised data relating to the thirteen patients who were alive twenty-four weeks after starting treatment with diamorphine.

| Medication | Number of patients |
|---|---|
| Phenothiazine | 13 |
| Glucocorticoid | 11 |
| Antidepressant | 7 |
| Other analgesic | 6 |

Table 5. Summary of adjuvant medication in thirteen patients surviving six months after commencing treatment with diamorphine.

In Case 1 the dose of diamorphine undulated. Several of the upward adjustments in the dose of diamorphine were for pain associated with different metastatic lesions. This fact coupled with the subsequent dose decreases suggests that, in this patient at least, increases in diamorphine were made because of increased pain rather than on account of tolerance.

In Case 3, where the dose chart shows three elevations, the first and third relate to clearly defined episodes. In both a new pain caused by fresh metastatic activity precipitated the increased requirement. In the second elevation, the recurrence of a previous pain led to the increase. At first sight, then, tolerance to diamorphine might be suspected. However, the ability to make a fourfold reduction in dose some three weeks later suggests that this elevation also resulted from an acute episode relating

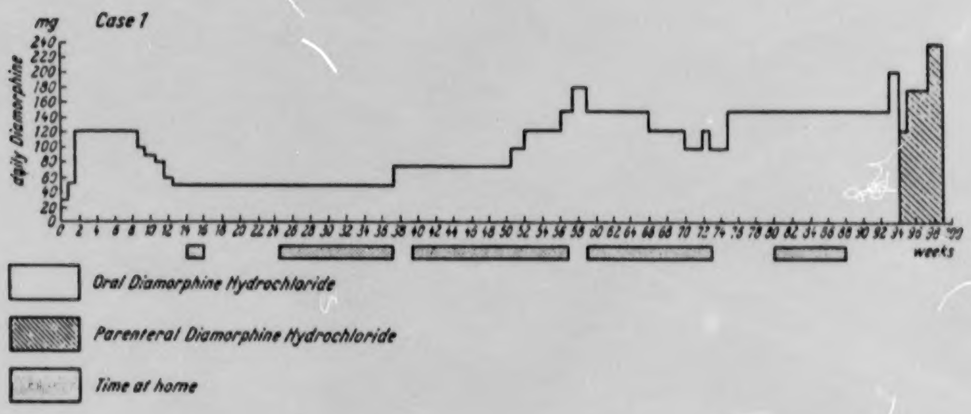


Figure 3.

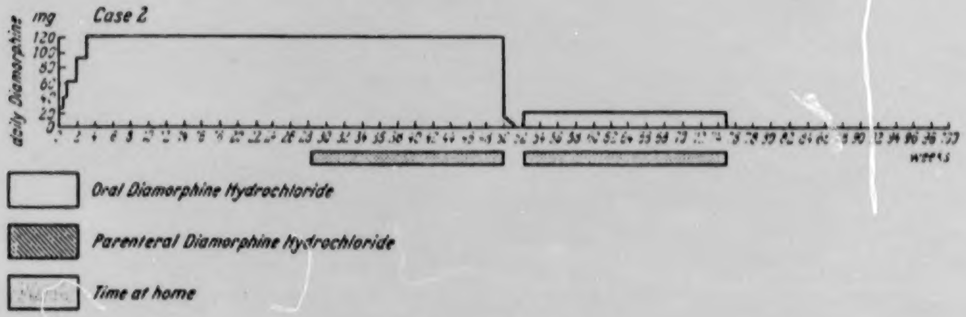


Figure 4.

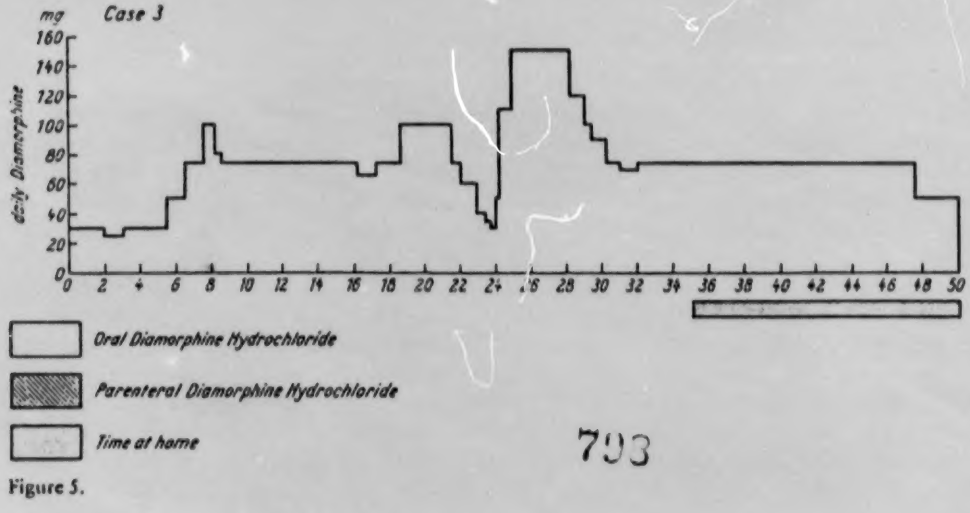


Figure 5.

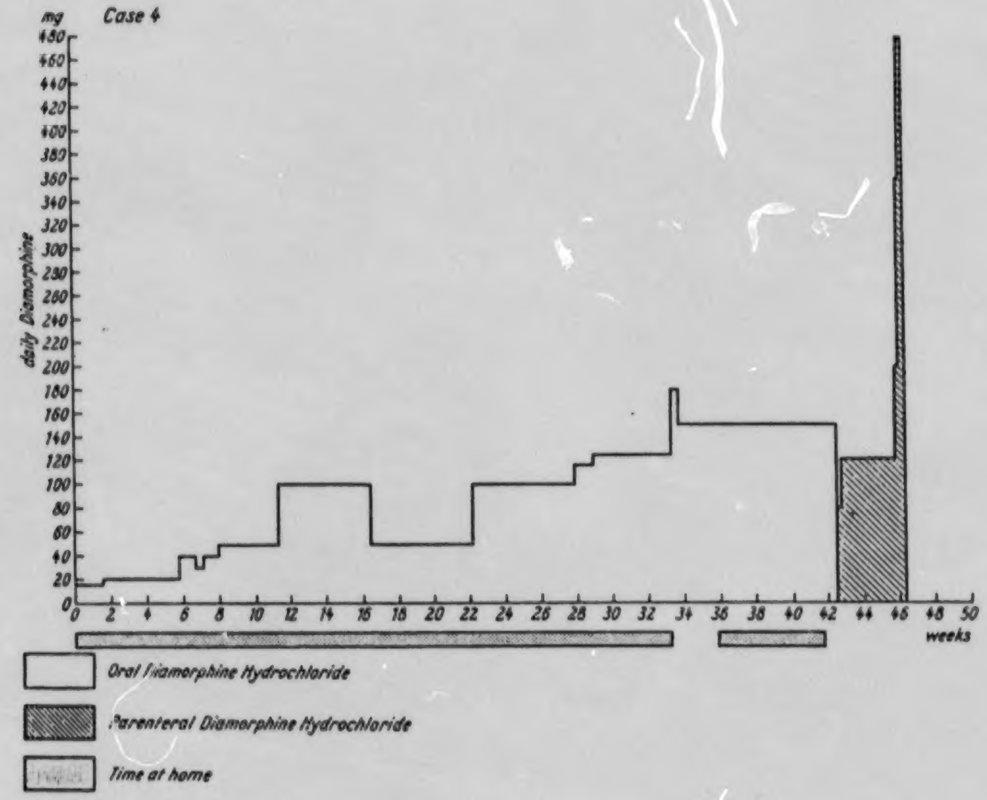


Figure 6.

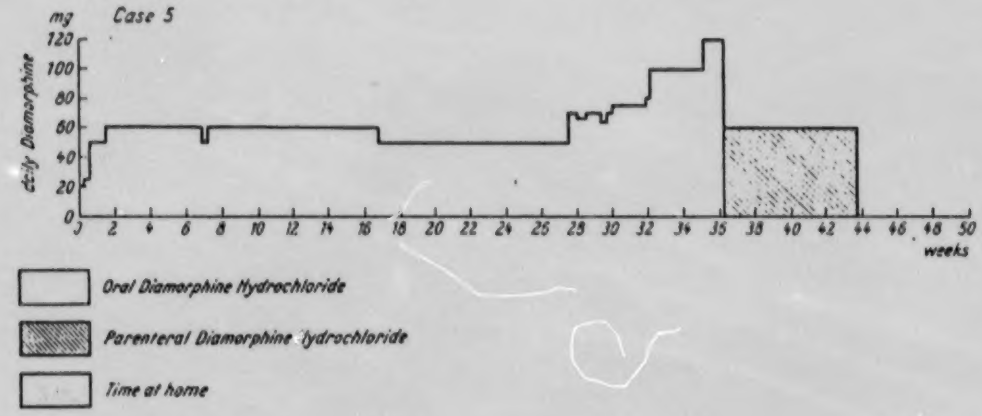


Figure 7.

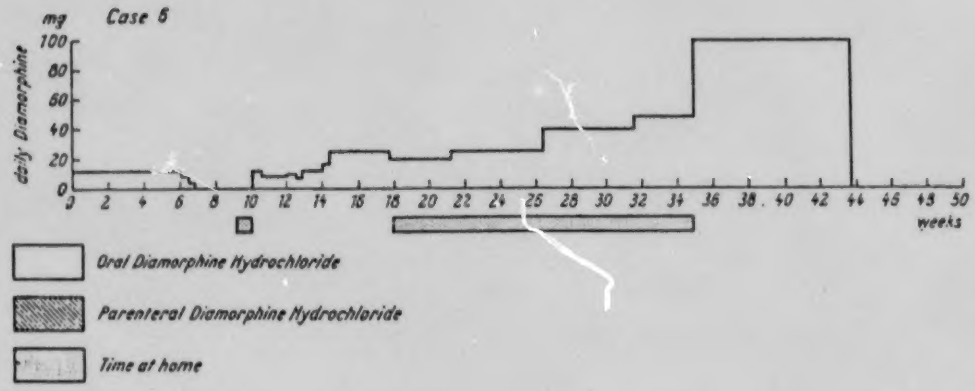


Figure 8.

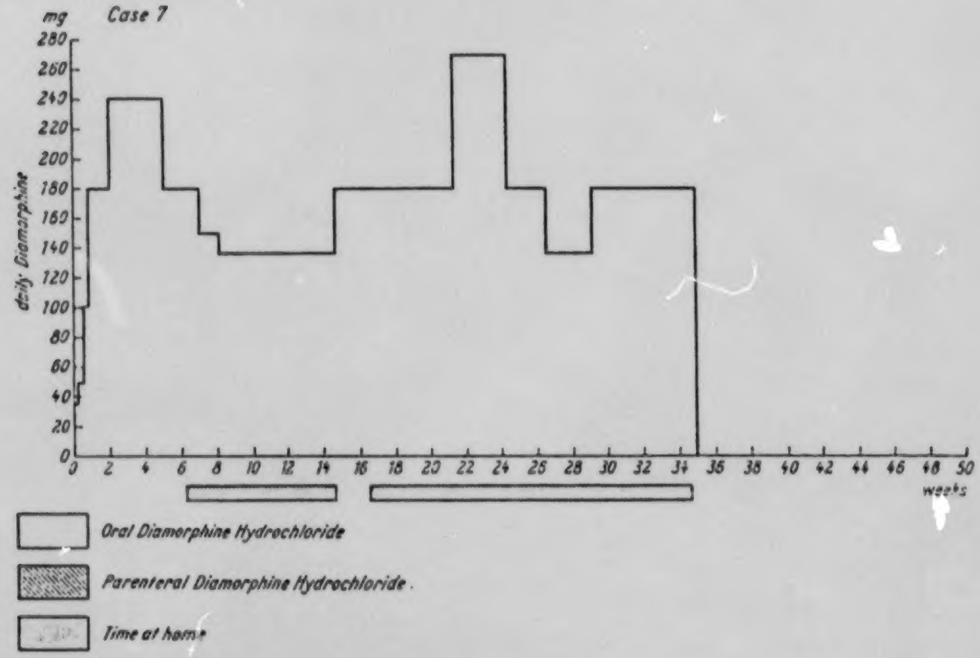


Figure 9.

to a bony metastasis. The final reduction, made by the patient's general practitioner, led to recurrence of intermittent discomfort demonstrating that the patient still required analgesia at this stage.

Case 8 is notable in that the patient required diamorphine by injection during the early part of treatment due to poor control of pain on the oral preparation. If we accept that, by injection, diamorphine is approximately

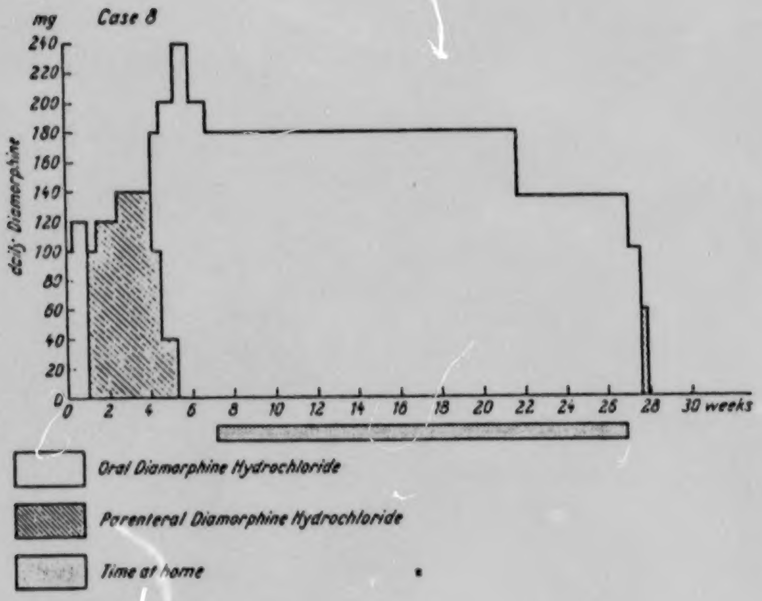


Figure 10.

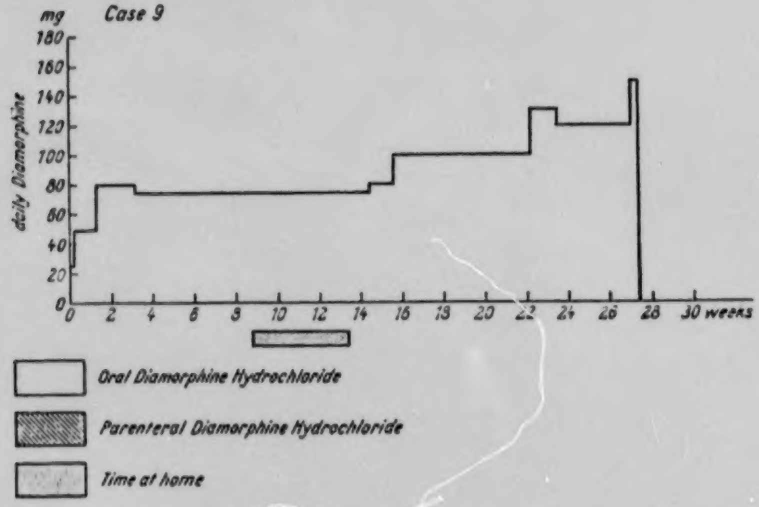


Figure 11.

twice as potent, this patient was receiving the equivalent of diamorphine 280 mg/day by mouth after three weeks. Subsequently, he reverted to oral therapy and it was possible, later, to reduce the dose still further. The pain, once controlled, did not recur apart from on one or two isolated occasions. In cases 12 and 13 it was possible to curtail treatment with diamorphine completely--the reduction in dose being linked to reduction in pain. Neither patient experienced symptoms attributable to withdrawal of diamorphine.

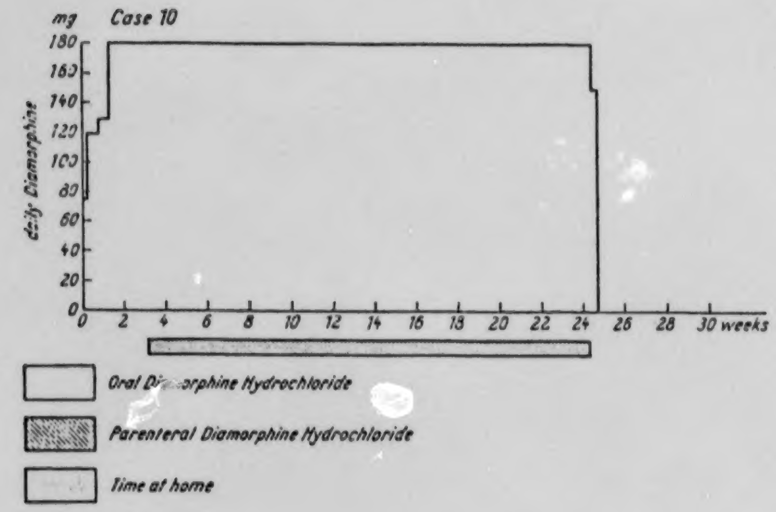


Figure 12.

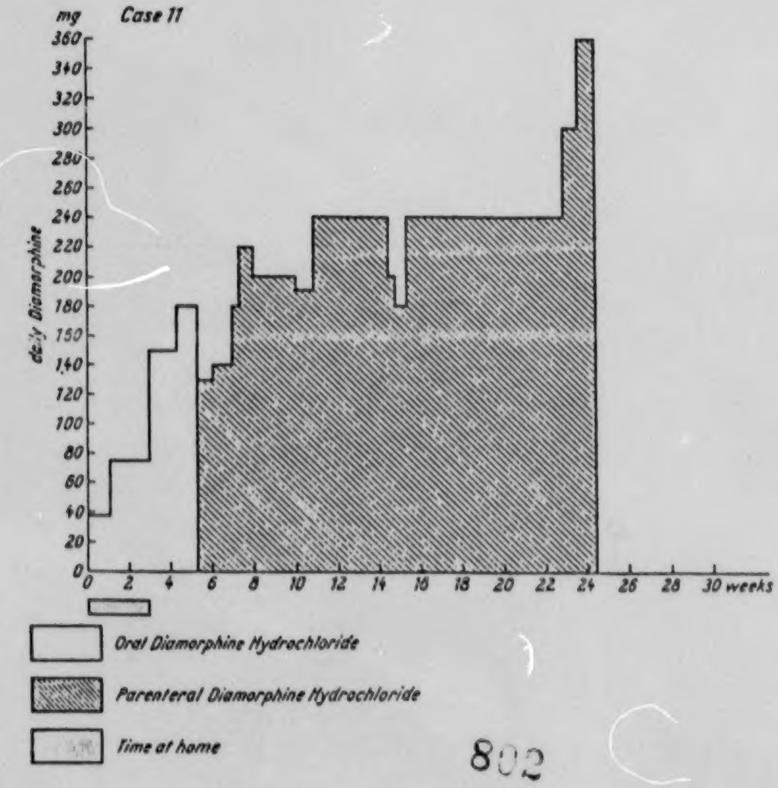


Figure 13.

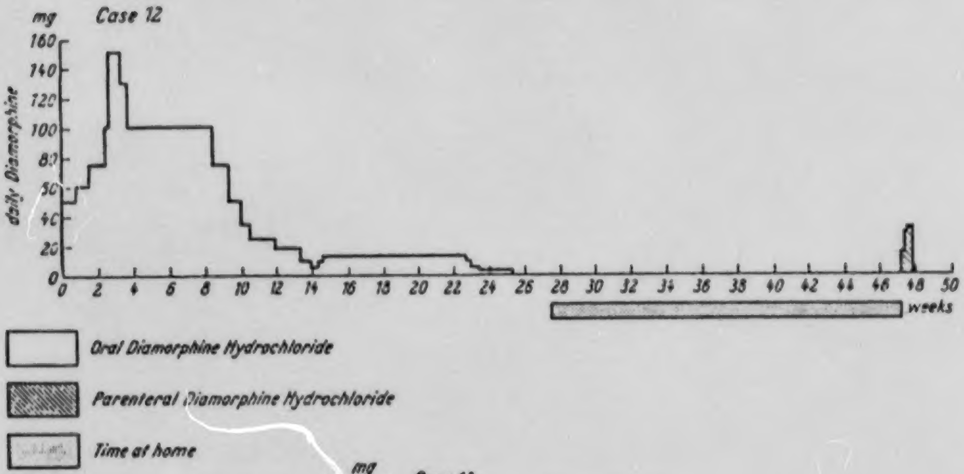


Figure 14.

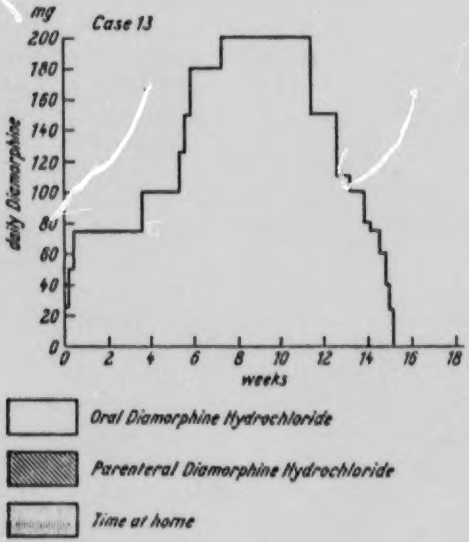


Figure 15.

Case 11 emphasises that treatment by injection is not incompatible with relatively long survival. It also reinforces the fact that, in our experience, only the minority of patients require parenteral treatment for any length of time.

In Case 10, the patient was discharged after only three weeks having been admitted with severe epigastric pain. The diamorphine was not increased during the five months she was at home despite the diagnosis of progressive carcinoma of the stomach. Case 2 was the other instance of a prolonged plateau-like dose-time graph. This patient was prescribed diamorphine more for general distress and dyspnoea than for pain. A year after beginning treatment he was admitted to another hospital for further investigation. The dose of diamorphine was immediately reduced to a tenth of its previous level without precipitating withdrawal symptoms. These appeared only when the diamorphine was completely stopped ten days later. Whether or not a less hasty termination of treatment would have prevented the appearance of the withdrawal symptoms is an open question. The outcome in Cases 12 and 13 suggests that the answer is in the affirmative.

## DISCUSSION AND CONCLUSIONS

Medical opinion, in general, has always urged caution in the use of narcotic analgesics, especially morphine and diamorphine. Fears of impairment of the patient's mental faculties (Bunyard, 1971), escalation of the effective dose (Milton, 1972) and addiction (British Medical Journal, 1964), appear to be main reasons for this. The aim of this review is to document part of the clinical experience that has been, and is being, accumulated at St. Christopher's Hospice and, by so doing, bring the whole subject into better perspective.

## ORAL MEDICATION

One of the more important facts to emerge is that the majority of patients can be maintained on oral therapy until death or until the last twelve or forty-eight hours before death when increasing debility makes oral administration difficult if not impossible. Recently we have started using higher oral doses, more than 40 mg, rather than changing to injections at this point should an increase be required. Our experience with such doses is still, however, limited.

## OPTIMAL DOSE OF DIAMORPHINE

Almost twenty years ago, Lasagna and Beecher (1954) defined the optimal dose of a drug as that dose which provides the desired therapeutic effects with a minimum of undesirable side effects. A study of the dose-response curve for morphine led them to conclude that the optimal dose was 10 mg per 70 kg of body weight. Although one cannot disagree with their definition of optimal dose, it was wrong to equate the dose above which the dose-response curve begins to flatten with the optimal dose. The optimal doses of diamorphine in the patients reviewed ranged from as little as 2.5 mg by mouth to 90 mg by injection the latter being equivalent to some 200 mg of injected morphine.

## IMPAIRMENT OF MENTAL FACULTIES

It has been suggested that the prescription of a potent narcotic analgesic to an inoperable cancer patient 'suffering agonies from chronic pain' was like sentencing the patient 'to a kind of living death' (Bunyard 1971). It is difficult to be sure exactly what was meant by a 'kind of living death' It probably refers to the common belief that patients receiving narcotic analgesics are in some way 'detached from reality' or simply lie 'drugged' in bed. However, one's own experience from treating several hundred patients with diamorphine is that this is not so. Indeed, in the present series of 500 patients, 46 were discharged for varying lengths of time and of these 22 were on diamorphine at the time of discharge. These patients were alert and mobile, though one or two of the more elderly ones required a walking frame. Their diamorphine requirements are given in Table 6. It appears that 150 mg of diamorphine a day by mouth is not incompatible with

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| Daily dose of diamorphine (mg) | Number of patients |
|---|---|
| 12.5 | 5 (4) |
| 25 | 1 (2) |
| 50 | 4 (2) |
| 100 | 8 (4) |
| 150 | 4 (10) |
| | 22 |

This figures in parentheses refer to the number of patients ultimately given dose while being cared for at home.

Table 6. Diamorphine requirements in 22 discharged patients.

normal activity. I would suggest that 'detachment from reality' - if it occurs - and drowsiness are related more to advanced physical debility than to any particular dose of diamorphine.

## TOLERANCE

The data in this review, especially those relating to patients who survived for twenty-four weeks or more after commencing treatment with diamorphine, supports the hypothesis that increases in dose are caused more by increased pain than by tolerance. There is certainly no foundation for the recent statement that, due to tolerance, morphine is no longer effective after three months of continuous use (Milton, 1972). In practice, when diamorphine is used as at St. Christopher's - regularly, prophylactically and as part of a programme of total patient care - tolerance, if it occurs, is not a practical problem.

## ADDICTION

Although the term 'drug addiction' has been replaced officially by 'drug dependence', unofficially it continues to be used. Drug dependence is currently defined as:

> "A state, psychic and sometimes also physical, resulting from the interaction between a living organism and a drug, characterised by behavioural and other responses that always include a compulsion to take the drug on a continuous or periodic basis in order to experience its psychic effects, and sometimes avoid the discomfort of its absence. Tolerance may or may not be present" (World Health Organisation 1969).

This is a broader definition than that of 1964 which emphasised the need for both tolerance and an early development of physical dependence in addition to strong psychic dependence (World Health Organisatiin, 1964). Thus the term drug dependence now more clearly approximates to the popular conception of addiction - a compulsion or overpowering drive to take the drug in order to experience its psychic effects.

On this definition none of the patients reviewed became addicted. Occasionally a patient has been admitted to the Hospice who appears to be addicted. Such a patient typically has a long history of poor pain control, is receiving regular but inadequate injections of a narcotic analgesic and who demands an injection every two or three hours. Usually, with time and patience, it is possible to control the pain adequately, prevent clock-watching and the demanding behaviour and, sometimes, even transfer patients on to an oral preparation. But even here, can it be said that the patient is truly addicted? Is he craving the narcotic in order to experience its psychic effects? Or, is he craving relief from his pain, in part if not in full, for at least an hour or two?

## PHYSICAL DEPENDENCE

It is possible but by no means certain that the majority of the 205 patients who received diamorphine for more than one week became physically dependent on it. Dependence was clearly demonstrated after a year in Case 2. In 1959 Eddy and his associates published a review of cancer patients maintained on subcutaenous morphine, oxymorphone and anileridine. They tested for physical dependence by injecting nalorphine hydrochloride 1 mg subcutaneously at fortnightly intervals. They were able to show that over half the patients had developed physical dependence by the end of the second week of treatment and that it was unusual for a patient not to be physically dependent by the end of the fourth week. All the patients were, however, receiving morphine by injection, whereas, according to Lee (1942), when administered by mouth dependence develops less rapidly and, possibly, to a lesser degree. Even so, whether or not physical dependence develops it does not prevent the gradual downward adjustment of dose nor the complete curtailment of treatment when this becomes clinically feasible.

## NOT A PANACEA

It must be clear from the summarised case histories that diamorphine cannot be regarded as a panacea for terminal cancer. For example, half the patients who survived twenty-four weeks after commencing treatment with diamorphine required tricyclic antidepressants. Unless it, or any other analgesic, is used within the context of total patient care, the results will be far from satisfactory.

We hope shortly to evaluate the benefit, if any, of the cocaine and to assess the adjunctive use of phenothiazines. Likewise the complex and complicating role of prednisone requires elucidation. For example, in Case 1, the patient was almost certainly hypercalcaemic when admitted; she improved rapidly and dramatically when prednisone was prescribed. Hypercalcaemia is known to precipitate or exacerbate pain in malignant disease and its correction to cause relief (Galasko & Burn, 1971). It is possible that alteration of the biochemical milieu in other ways can alter the pain threshold and thus a patient's narcotic requirement.

Even though many questions remain unanswered it seems likely that many commonly accepted facts concerning the long-term use of narcotics are probably little more than folklore, handed down from one medical generation to the next. It is the author's hope that the data contained in this review will go some way to raising the subject from the realm of folklore into that of scientific fact.

The author wishes to thank Miss Elizabeth Spinks for collating much of the provisional data. He is in receipt of a research fellowship from the Sir Halley Stewart Trust. The work was supported by a grant from the Department of Health and Social Security.

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March 1979 pg. 751.

EDITORIALS

# MORPHINE SANS THE GIFT OF MORPHEUS

Leroy D. Vandam, M.D.

The leading edge of discovery on pain moves forward in one of its recurrent accelerations. Several phenomena have contributed to this resurgence. The first is the perennial human fascination with the sensation of pain and the natural impulse to relieve suffering. Secondly, some of the older ideas concerning pain perception, the specificity and pattern theories, have been supplanted by a hypothesis based on a gating mechanism in the spinal cord, which regulates traffic in pain impulses. Even acupuncture, that once hailed, now disparaged, therapeutic measure, has added to the ferment through attempts to comprehend its mechanism. Thirdly, and rationally so, are the multifold clinical pharmacologic studies on new kinds of drugs, the elucidation of the mode of action of some of the older analgetics and the current excitement over the role of endorphins so far as exogenous drug activity is concerned.[1] In this issue of the *Journal*, a report from a Veterans Administration Cooperative Study Group on the combined use of a euphoretic drug and morphine, falls into the third category.

Nobody would deny the analgetic effectiveness of morphine or, for that matter, of any of the opioid congeners or synthetic substitutes. Unfortunately, the ceiling on optimum relief of pain is lowered by an assortment of adverse effects as dosage is increased. In that department, respiratory depression, a peculiar union of sedation and dysphoria, and nausea and vomiting head the list, followed by a lengthening tail of postural hypotension, mixed stimulation and depression of smooth muscle in gut and urinary tract and, of course, the addiction possibility. As in other therapies, one approach to either enhancement of drug action or counteraction of adverse effects lies in combined drug usage. Thus, the opioids have been tried in conjunction with stimulants, tranquilizers or narcotic antagonists. None of these stratagems have caught on simply because the putative advantages of each drug do not exactly coincide either qualitatively or temporally and fixed drug combinations are anathema.

Forrest et al., of the Veterans Administration, would enhance analgesia obtained by morphine with dextroamphetamine while simultaneously countering somnolence and respiratory depression. They have to some extent succeeded in this endeavor, but the pluses and minuses deserve scrutiny. Resorting to standard procedure of quantitating pain relief in pathologic pain, a group of 450 otherwise healthy young patients were given morphine or morphine plus amphetamine to relieve the severe pain of abdominal or orthopedic operations. Pain-relief scores were definitely improved with lesser amounts of morphine as amphetamine was added; the effect on wakefulness was less apparent. Although respiratory reserve was not actually challenged, the increase in respiratory rate suggests that breathing was not impaired. Besides, as everyone knows, wakefulness stimulates breathing. Changes in pulse rate and blood pressure showed no uniform trends, but not too surprising were the appearance of excessive sweating, a tendency toward more dizziness and nausea and a scattering of unusual phenomena in the form of visual disturbances, body tremors and flushing. The authors do not state whether the subsequent requirement for morphine was diminished or if the characteristic responses to amphetamine could be cumulative. How would the combination work in the elderly, in whom adverse psychic effects of drugs are easily evoked and myocardial stimulation and arrhythmias should be avoided? Could the combined smooth-muscle depressant properties of the two drugs result in a higher rate of urinary retention and ileus after operation in any age group? In treatment of chronic pain one might surely anticipate mutual enhancement of addiction to either drug. Finally, so far as postoperative alertness is concerned, how many would elect to relinquish the "sleep that knits up the ravell'd sleave of care"? Apparently, the Veterans Administration Group would opt to doze, for they have lately waxed equally enthusiastic over a combination of morphine and hydroxyzine (Vistaril), an ataractic compound.[2]

If these imaginative approaches to relief of pain do not bear fruit clinically, perhaps the knowledge gained of the mechanisms at work will prove useful. The obvious interpretation is that two drugs so employed, of whatever kind, are mutual antagonists-a hypothesis underlying the use of analeptics in drug poisoning. So far as analgesia is concerned, the sympathomimetic amines, amphetamine among them, owe their actions more or less to the release of endogenous catecholamines, both centrally and peripherally. And epinephrine per se has been shown to have analgetic properties. Thus, as has been the experience with psychotherapeutic drugs, endogenous release of bioamines alters mood - and why not the affective component of pain at receptor sites or via the complex array of synapses involved in the processing? Although it is unlikely that receptor activity is directly implicated here, perhaps the endorphins have a role. Amphetamine and other antidepressants act noradrenergically at the hypothalamic level to liberate releasing factors. Administration both of dopamine and of norepinephrine results in the appearance of thalamic releasing factors that play upon the hypophysis. And substances with opiate-like activity, morphinomimetic peptides, have been recovered from porcine hypothalamic-neurohypophyseal extracts.[1] The possibilities are legion and enchanting. This is why we ride upon the rapidly moving edge of discovery!

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# FAILURE OF HIGH-DOSE VITAMIN C (ASCORBIC ACID) THERAPY TO BENEFIT PATIENTS WITH ADVANCED CANCER

Reprint by permission: New England Journal of Medicine. Vol. 301, No. 13, Sept. 1979, pp. 687-690.

## A Controlled Trial

Edward T. Creagan, M.D., Charles G. Moertel, M.D., Judith R. O'Fallon, Ph.D., Allan J. Schutt, M.D., Michael J. O'Connell, M.D., Joseph Rubin, M.D., and Stephen Frytak, M. D.

ABSTRACT One hundred and fifty patients with advanced cancer participated in a controlled double-blind study to evaluate the effects of high-dose vitamin C on symptoms and survival. Patients were divided randomly into a group that received vitamin C (10 g per day) and one that received a comparably flavored lactose placebo. Sixty evaluable patients received vitamin C and 63 received a placebo. Both groups were similar in age, sex, site of primary tumor, performance score, tumor grade and previous chemotherapy. The two groups showed no appreciable difference in changes in symptoms, performance status, appetite or weight. The median survival for all patients was about seven weeks, and the survival curves essentially overlapped. In this selected group of patients, we were unable to show a therapeutic benefit of high-dose vitamin C treatment. ( N Engl J Med 301:687-690, 1979)

The possible role of vitamin C in both the pathogenesis and therapy of malignant disease has been suggested by a variety of laboratory and clinical data. A deficiency of ascorbate has been reported in association with dissolution of the intercellular matrix, which might facilitate local infiltration and dissemination of neoplastic cells.[1] Studies in laboratory animals have shown that ascorbate seems to concentrate in malignant tissue and thus depletes systemic reserves.[2-4] Moreover, in patients with skin carcinoma, concentrations of vitamin C are higher in the tumor than in the surrounding normal tissue.[5] Lymphocytes, mediators of cellular immunity, contain relatively high amounts of ascorbate, and immune responsiveness has been enhanced by ascorbate administration in mice.[6] Moreover, there have been some apparent regressions of adenomas after administration of ascorbate by mouth in persons with familial polyposis coli, a known premalignant condition.[7]

Several nonrandomized studies have suggested that high-dose vitamin C (10 g per day by mouth) might enhance survival and improve symptoms of patients with advanced cancer. Cameron and Campbell studied 50 such patients who had not received chemotherapy and reported five tumor regressions (10 per cent).[8] These authors also reported that most patients experienced some subjective benefit.[8] In a later report, 50 patients who had previously received irradiation and chemotherapy were combined with the first group, and the survival of all 100 patients was compared with that of 1000 historical control cases in the records at the Vale of Leven Hospital, Loch Lomondside, Scotland.[9]

For each ascorbate-treated patient, 10 controls were matched on the basis of age, sex, site and histologic features of the primary tumor. The mean survival of patients given ascorbate was 210 days, as compared with 50 for the selected controls. Since this was not a randomized study, doubt has been raised concerning the comparability of ascorbate-treated patients and the control population.[10] Cameron and Pauling therefore revised the original study group to exclude 10 ascorbate-treated patients with unusual cancers; they substituted 10 other patients randomly selected from the records of ascorbate-treated patients at the Vale of Leven Hospital.[11] In addition, a new group of 1000 controls was selected because data on some of the initial control patients were considered unreliable and incomplete. Most of the new controls, however, were drawn from the original control population. This revised and updated analysis showed that the mean survival of patients given vitamin C was greater than 293 days, as compared with 38 for the controls.

Since bias is possible in nonrandomized studies including selected controls, we conducted a randomized, controlled double-blind trial to evaluate the effect of vitamin C on symptoms and survival in patients with advanced and preterminal cancer.

## PATIENTS AND METHODS

All patients had histologically documented advanced cancer, and all were able to take medications by mouth. All were unsuitable for treatment with systemic chemotherapy, either because of progression of disease after previous efforts or because their general condition precluded cytotoxic regimens.

Relatively few pediatric patients met the eligibility criteria. No patients had leukemia. Patients were stratified on the basis of a performance score of 2 versus 3 or 4 on the Eastern Cooperative Oncology Group scale (in which a score of 0 indicates a fully active patient, whereas 4 indicates bedridden); patients with a scope of 3 or 4 were grouped as one stratum. The patients were also classified on the basis of site of primary tumor (colon, stomach, lung, pancreas, breast and other) and then randomized to one of two groups: those given vitamin C (10 g per day by mouth in four divided doses, or a total of twenty 0.5-g capsules daily) and those given the same number of capsules containing a comparably flavored lactose placebo. Both drugs were given as identical capsules, dispensed in bottles of 1000, which were identified only by code number. The drug supply was renewed at six-week intervals as needed. Neither patient nor investigator knew which drug was being administered. Treatment was continued until death or until the patient was no longer able to take medications by mouth. At two-week intervals, patients reported the amount and frequency of the drug taken, the status of their symptoms and body weight.

A total of 150 patients were entered into the clinical trial. Patient and tumor characteristics for the 123 patients who took the study medication are listed in Tables 1 and 2. Twenty-seven patients elected not to participate after randomization, but before taking the first dose of vitamin C or placebo. These patients (12 assigned randomly to the placebo group and 15 to

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the vitamin C group) were considered unevaluable for comparative drug effects but were analyzed separately for survival. Their characteristics are shown in Table 3.

Chi-square tests of homogeneity were performed to compare the distributions of the following five pretreatment clinical characteristics between the two treatment groups: age, sex, site of primary tumor, initial performance score and previous treatment. Kaplan-Meier survival curves were plotted separately for the two treatment groups and tested for inequality by use of the Gehan-Wilcoxon and log-rank tests. A Cox covariate analysis was performed, using the survival data from the 123 treated patients.[12]

Table 1

Patient Characteristics

| Characteristic | Vitamin C Group | Placebo Group |
|---|---|---|
| No. of Patients | 60 | 63 |
| Age, year | | |
| $\leq 45$ | 2 | 4 |
| 46-65 | 26 | 27 |
| >65 | 32 | 32 |
| Sex | | |
| Male | 37 | 39 |
| Female | 23 | 24 |
| Performance Score* | | |
| 2 | 12 | 13 |
| 3 | 39 | 43 |
| 4 | 9 | 7 |

*Eastern Cooperative Oncology Group score: 0 (fully active) to 4 (totally disabled).

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## Table 2

## Tumor Characteristics and Previous Treatment

| Characteristic | Vitamin C Group | Placebo Group |
|---|---|---|
| No. of Patients | 60 | 63 |
| Site | | |
| Colorectal | 24 | 26 |
| Pancreas | 12 | 12 |
| Lung | 6 | 6 |
| Stomach | 5 | 3 |
| Other | 13 | 16 |
| Grade of Anaplasia (Broder's) | | |
| 1,2 | 29 | 27 |
| 3,4 | 17 | 23 |
| Not stated | 14 | 13 |
| Previous treatment | | |
| None | 5 | 4 |
| Radiation therapy | 17 | 18 |
| Chemotherapy | 52 | 56 |

## Table 3

### Characteristics of 27 Patients Who Took No Study Drug

| Characteristic | No. of Patients |
|---|---|
| Age, year | |
| ≤45 | 1 |
| 46-65 | 13 |
| >65 | 13 |
| Sex | |
| Male | 19 |
| Female | 8 |
| Performance score* | |
| 2 | 3 |
| 3 | 19 |
| 4 | 5 |
| Previous treatment | |
| None | 7 |
| Radiation therapy | 9 |
| Chemotherapy | 17 |
| Site of primary tumor | |
| Colorectal | 4 |
| Pancreas | 4 |
| Lung | 4 |
| Stomach | 4 |
| Other | 11 |
| Grade of anaplasia (Broder's) | |
| 1,2 | 6 |
| 3,4 | 16 |
| Not stated | 5 |

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*Eastern Cooperative Oncology Group score: 0 (fully active) to 4 (totally disabled).

## RESULTS

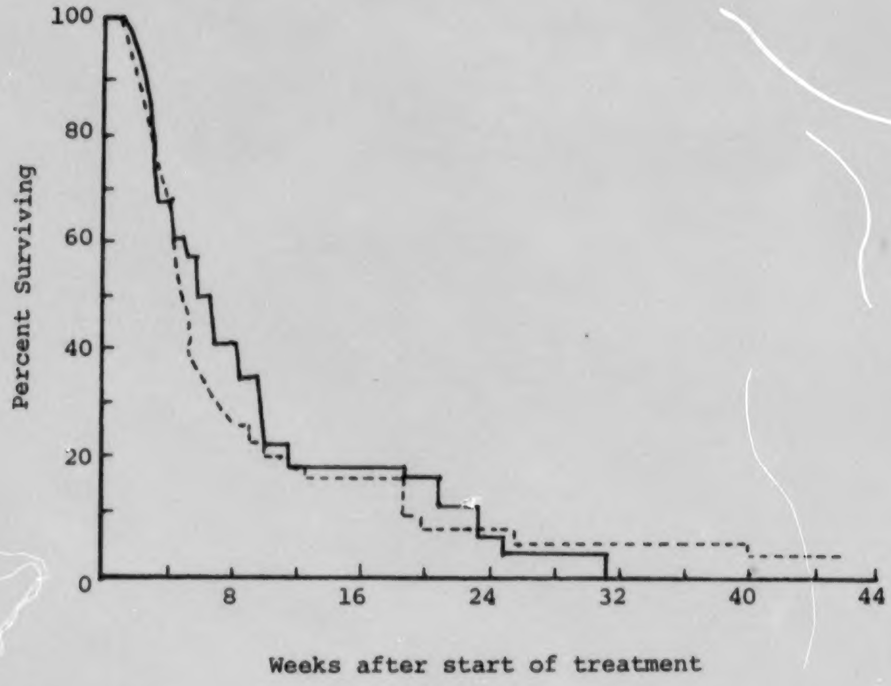
### Survival

The survival curves for the 123 patients treated with vitamin C and with placebo are shown in Figure 1. There was no significant difference in survival between the two groups (log-rank test; P=0.61). We were unable to show any survival benefit according to tumor site. Note that the two treatment groups are evenly balanced in age, sex, site of primary tumor, initial performance status and previous treatment (Tables 1 and 2).

Figure 1

High-Dose Vitamin C versus Placebo and
Survival Results in Patients with Advanced Cancer

The solid line shows survival in 60 patients given vitamin C. The dashed line shows survival in 63 patients given the lactose placebo.



Cox covariate analysis showed that none of the six potentially prognostic factors was significantly associated with survival in the 123 treated patients. Only performance score was even marginally associated (P=0.08) after taking into account the effects of the remaining factors.

The one long-term survivor in this study is a patient with metastatic islet-cell carcinoma, massive hepatomegaly and jaundice who had shown no response to many previous attempts at chemotherapy. After entering the study, he showed improvement in symptoms and some reduction in serum bilirubin. He was still alive 63 weeks after entering the study. This patient received the lactose placebo.

## Symptom Reduction and Side Effects

Fifty-eight per cent of the patients given the placebo and 63 per cent of those given vitamin C claimed some improvement in symptoms during treatment. There were no statistically significant differences in symptoms between the two treatment groups (Table 4).

Mild nausea and vomiting were the most frequent toxic reactions, affecting about 40 per cent of patients, but there were no statistically significant differences in the number of episodes between the two groups (Table 4). There was no noteworthy excess of heartburn or other upper-gastrointestinal-tract symptoms in patients given vitamin C, nor was there any documented occurrence of renal calculi.

Table 4

Symptomatic Results and Side Effects

| | Vitamin C Group | | Placebo Group | |
|---|---|---|---|---|
| | No. | % | No. | % |
| Improvement | | | | |
| Appetite | 14/53 | 26 | 12/52 | 23 |
| Strength | 14/53 | 26 | 7/53 | 13 |
| Activity level | 22/53 | 42 | 22/53 | 42 |
| Pain control | 12/49 | 24 | 7/48 | 15 |
| Toxicity | | | | |
| Nausea | 27/60 | 45 | 27/63 | 43 |
| Vomiting | 22/60 | 37 | 22/63 | 35 |
| Heartburn | 16/60 | 27 | 15/63 | 24 |
| Diarrhea | 20/60 | 33 | 20/63 | 32 |
| Leg Swelling | 34/60 | 57 | 28/63 | 44 |
| Other | 30/60 | 50 | 26/63 | 41 |

## Analysis of Untreated Patients

An interesting group of patients in this study are those who accepted randomization but subsequently elected not to participate. These patients, in a nonrandomized study, would be presumed to be included only in the non-treated historical controls (Table 3). These patients were excluded from the above analysis because they would not show evidence of the effect of vitamin C or placebo.

The 27 patients who did not receive treatment had a significantly worse (log-rank test; P=0.017) survival than the 123 patients who did take the medication. The median survival in the untreated patients was 25 days, as compared with 51 for treated patients.

## DISCUSSION

We were unable to demonstrate any statistically significant benefit of high-dose vitamin C in selected patients with advanced cancer. It should be noted, however, that only nine of our 123 patients had not previously received chemotherapy or radiation therapy. It is therefore impossible to draw any conclusions about the possible effectiveness of vitamin C in previously untreated patients. In Cameron and Campbell's report of a 10 per cent regression rate in 50 patients with widely disseminated cancer, none had received definitive prior treatment and presumably were more immunocompetent than our patients. Since vitamin C may have an impact on host resistance to cancer,[13] we recognize that earlier immunosuppressive treatment might have obscured any benefit provided by this agent. Nevertheless, the nonrandomized study[9] that showed a fourfold enhancement of survival with vitamin C included patients who had received conventional cancer treatment (i.e., cytotoxic agents and radiation therapy). This improvement could not be substantiated by our study.

There is evidence that vitamin C maintains immunocompetence. Although patients with advanced cancer who have previously been treated with irradiation or chemotherapy are indeed immunosuppressed, they are not totally incapable of mounting an immune response. In two previous studies of patients with advanced cancer who were selected on the basis of essentially the same criteria used in this study, we found that 80 per cent were capable of responding to recall skin tests (O'Connell MJ, O'Fallon JR, Ritts RE, et al: unpublished data), and 56 per cent responded to dinitrochlorobenzene.[14] One might expect, therefore, that vitamin C would exert some restorative influence in patients whose immune apparatus has been compromised by earlier treatment efforts. If such an effect did occur in our patients, it was not seen in their clinical improvement.

We cannot recommend the use of high-dose vitamin C in patients with advanced cancer who have previously received irradiation or chemotherapy.

We are indebted to Mrs. H. Golenzer, Mrs. T. Hu and Mrs. R. Rogers for their support and cooperation.

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# MODULE VII-B PAIN AND SYMPTOM MANAGEMENT

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# MODULE VII-B: PAIN AND SYMPTOM MANAGEMENT

## PURPOSE AND GOALS

The purpose of Module VII-B is to assist the hospice care nurse to intervene more effectively to relieve the symptoms experienced by patients. The goals of this module are to assist participants to:

- Identify factors which contribute to the symptoms experienced by patients
- Develop alternative interventions to provide symptom relief
- Evaluate the effectiveness of interventions

## MODULE CONTENT

- Overview: Symptom Management
- Pain
    - Causes of pain
    - Attitudes related to pain
    - Assessment of pain
    - Interventions to modify pain
- Nutritional Impairments and Related Problems
    - Rationale
    - Anorexia
    - Nausea, Vomiting
    - Taste Disturbances
    - Stomatitis
    - Nutritional Assessment
    - Strategies for Modifying Food Intake
- Problems of Elimination - Bowel
- Incontinence
- Problems Related to/Resulting in Immobility
    - Edema
    - Thrombophlebitis
    - Decubiti
    - Pathologic Fractures

- Infection
- Fatigue
- Dyspnea

## LEARNING OBJECTIVES

Using the information presented in this module as criteria, at the end of this module, and without aid of notes, participants will be able to:

1. Identify factors which contribute to the symptoms of pain, anorexia, nausea/vomiting, taste disturbances, stomatitis, constipation, diarrhea, incontinence, edema, thrombophlebitis, decubiti, pathologic fractures, infection, fatigue and dyspnea.
2. Describe relationships between symptoms.
3. Suggest data which are necessary to obtain to be able to plan interventions for the symptoms of pain, anorexia, nausea/vomiting, taste disturbances, stomatitis, constipation, diarrhea, incontinence, edema, thrombophlebitis, decubiti, pathologic fractures, infection, fatigue and dyspnea.
4. Suggest alternative interventions to provide relief from the symptoms of pain, anorexia, nausea/vomiting, taste disturbances, stomatitis, constipation, diarrhea, incontinence, edema, thrombophlebitis, decubiti, pathologic fractures, infection, fatigue and dyspnea.
5. Identify side effects of interventions.
6. Evaluate the appropriateness of interventions for the individual patient.
7. Evaluate the effectiveness of specific interventions.

## PERSPECTIVE

Symptom management can be an appropriate and rewarding focus for nursing. Regardless of the progress of a disease, there is always something that can be done to at least partially improve symptomatology. Essential to this process are clear problem identification, realistic goal setting and creative problem solving. This module attempts to provide the nurse with the necessary information to be able to help patients/families/caregivers define symptom related problems more clearly and set realistic goals. The emphasis, however, is on developing a pool of interventions for specific problems from which the nurse is able to draw,

Pain and nutritional problems are emphasized both because they constitute the most common and most distressing problems but also because there are so many things that can be done that are often not done in these areas.

This module is addressed to the nurse. This does not suggest that utilization of a team approach is not considered. But, a nurse does have the background and skill to do all that is suggested. Utilizing other team members will increase the likelihood of clear problem identification as well as the kinds of alternatives available for care. However, even in those situations where the nurse does not have any resources readily available, much can be done. And, even when a multidisciplinary team is in operation there is no reason for the nurse to be lacking in knowledge of aspects of critical importance to total patient care.

## SPECIAL PREPARATION AND DELIVERY REQUIREMENTS

Module VII-B is designed for a total delivery time of 8 hours. The module is divided into the following eight submodules.

| | |
|---|---|
| Submodule A: | Overview |
| Submodule B: | Pain |
| Submodule C: | Nutrition |
| Submodule D: | Problems of Elimination |
| Submodule E: | Problems Related to/Resulting from Immobility |
| Submodule F: | Infection |
| Submodule G: | Fatigue |
| Submodule H: | Dyspnea |

It has been our experience that each participant group brings its own unique level of knowledge and skills in the management of the above symptoms. The knowledge and skill demands in this area upon the hospice nurse also differ depending on the setting (hospital, homecare, etc.) and on the types of patients seen in the hospice program (via admission criteria). To adequately address these differing learning needs, we have not prepared a standardized delivery format for this module. The instructors for this module will be expected to select submodules and a delivery sequence based on the learning needs of each participant group.

The instructors should begin by asking each participant to complete the Pain and Symptom Management Knowledge and Skill Inventory (see sample on following page). This should be done as part of the course registration or at the beginning of the course to give the instructors time to review the data and design the module delivery schedule. The completed inventories should be reviewed to identify areas of greatest and least emphasis. Based on the above data, the instructors should:

1. Decide those submodules that will be eliminated or minimally reviewed for the module delivery
2. Decide those submodules (averaging scores of 4 to 5) that will be allocated the greatest amount of delivery time
3. Outline a delivery sequence for the submodules
4. Prepare a detailed instructional schedule outlining submodules, lectures, learning exercises, instructional assignments and approximate times

The material in the Instructional Activity Sequence at the conclusion of this module can be utilized by the instructors to prepare for whichever submodules have been selected for delivery.

Once the module design has been determined, the instructors should select articles, diagrams and any other instructional materials that will need to be reproduced and distributed to the participants.

## STAFF REQUIREMENTS

This module can best be presented utilizing two instructors. It is ideal if the two instructors bring separate strengths in hospital and home care nursing service. The optimum group size for the module is 20 with a maximum effective number of 30. Due to the nature of the material, instructors must ideally:

(SAMPLE: TO BE COMPLETED BY EACH PARTICIPANT)

## PAIN AND SYMPTOM MANAGEMENT
## KNOWLEDGE AND SKILL INVENTORY

Listed below are fifteen symptoms or conditions the hospice nurse is called upon to manage. Reflect on your education, training and experience in managing each of these symptoms. Indicate those symptoms you feel should receive the greatest emphasis during Module VII-B. Circle the number below that indicates your need for information on the assessment and management of each of the symptoms.

Circle the appropriate rating
for each symptom

| | Least Emphasis | Less Emphasis | Emphasize | More Emphasis | Most Emphasis |
|---|---|---|---|---|---|
| Symptom/Condition | 1 | 2 | 3 | 4 | 5 |
| 1. Pain | 1 | 2 | 3 | 4 | 5 |
| 2. Anorexia | 1 | 2 | 3 | 4 | 5 |
| 3. Nausea/Vomiting | 1 | 2 | 3 | 4 | 5 |
| 4. Taste disturbances | 1 | 2 | 3 | 4 | 5 |
| 5. Stomatitis | 1 | 2 | 3 | 4 | 5 |
| 6. Constipation | 1 | 2 | 3 | 4 | 5 |
| 7. Diarrhea | 1 | 2 | 3 | 4 | 5 |
| 8. Incontinence | 1 | 2 | 3 | 4 | 5 |
| 9. Edema | 1 | 2 | 3 | 4 | 5 |
| 10. Thrombophlebitis | 1 | 2 | 3 | 4 | 5 |
| 11. Decubiti | 1 | 2 | 3 | 4 | 5 |
| 12. Pathological fractures | 1 | 2 | 3 | 4 | 5 |
| 13. Infection | 1 | 2 | 3 | 4 | 5 |
| 14. Fatigue | 1 | 2 | 3 | 4 | 5 |
| 15. Dyspnea | 1 | 2 | 3 | 4 | 5 |

- Have strong educational preparation in the biological sciences
- Be Registered Nurses with a minimum of three years experience in medical-surgical or oncological nursing
- Have worked in a hospice program or in a palliative care oncology unit
- Have experience working with dying patients and their families in the homesetting
- Have a current knowledge of management techniques for severe chronic pain of physical origin
- Have one or more years experience in skill oriented instruction of health professionals

## SPACE REQUIREMENTS

It is useful for students to be able to work in triads during the portion of the module related to interventions for pain. However, recognizing that space considerations are often difficult to negotiate this module can be accomplished in a standard classroom setting provided: 1) all can easily see the screen/blackboard; 2) at times, groups of two or three participants can easily speak with one another for brief periods of time (five minutes).

## MATERIAL NEEDS

The equipment and material needs for Module VII-B include:

- Handouts as determined by submodule selection
- Overhead projector
- Transparencies for each module
- Prepared flip charts
- Specific materials for Module Components:
    - Nutrition for Patients Receiving Radiation and Chemotherapy, ACS Booklet
    - Nutrition: A Helpful Ally in Cancer Therapy (Ross Laboratories)
    - Suggest several foods from above or from Aker, 1979 when discussing nutritional interventions

Suggestions: Peanut butter, oatmeal cookies in ACS booklet,
Coconut pie in Aker

- Silastic feeding tube
- Leg bag
- Various ostomy appliances or pictures
- Hollister ostomy booklets

## INSTRUCTIONAL ACTIVITY SEQUENCE

The content outlines for each of the submodules are presented on the following pages. The sequence and time allocations will differ according to the instructional design selected by the instructors.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

SECTION A: SYMPTOM MANAGEMENT--RELEVANCE TO HOSPICE CARE

I. Goal of care is to minimize the deleterious effects of the symptoms which plague a patient because of disease or its treatment

II. Interdisciplinary team approach

- A. No one caregiver has all the information/ skills to address the multiple, interacting problems
- B. The nurse has the educational background, breadth of skills, understanding of both physiology and human behavior to serve as coordinator of this process

III. Symptoms included in this module were identified in survey by HCS, Inc. and in previous data compiled by the primary author

- A. Symptoms covered include: pain, anorexia, nausea, vomiting, infection, immobility related problems, incontinence, diarrhea, constipation, fatigue and dyspnea

IV. Philosophy

- A. Regardless of the progress of the disease, there is always something that can be done to at least partially improve symptomatology
- B. The positive rewards for both caregiver and patient/family are related to clear, realistic problem identification, the setting of realistic goals and the creativity of approaches to resolution of the problem

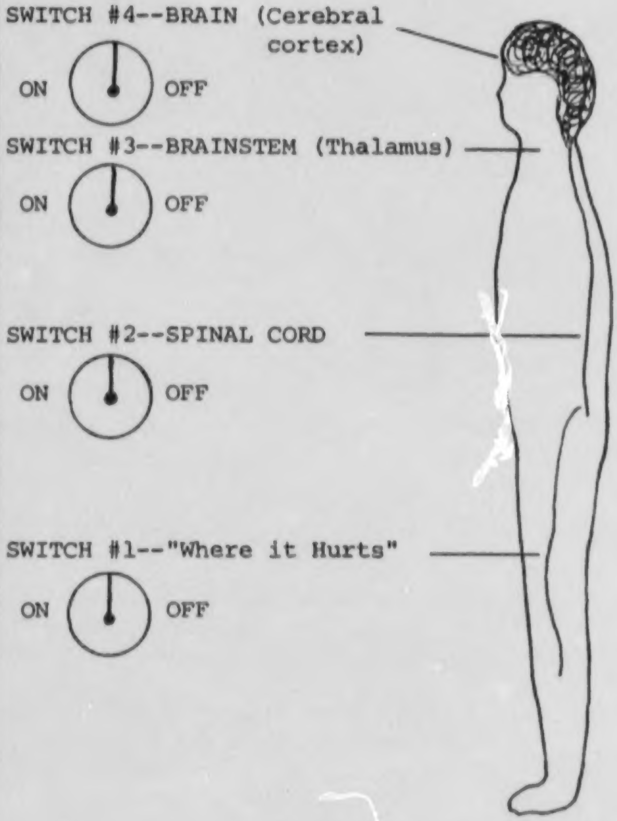
V. Overview of approach to module

- A. The cause(s) of symptoms are explored
- B. Assessment data is suggested:

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | 1. For a given patient all or very little of the data suggested may be appropriate to obtain<br>2. One must always balance the risk of increased fatigue and trauma to the patient against the potential benefit to the patient of continuing the assessment to learn more<br>C. Approaches to preventing, minimizing or overcoming the symptom are suggested:<br>1. Some approaches are appropriate only for patients with at least a prognosis of several weeks<br>2. As treatment improves the condition, even the terminally ill need to be treated more like chronically ill; emphasis remains on living rather than dying<br>3. Some approaches are more appropriate for patients who are also receiving some active treatment (at least of a pallative nature)<br>4. Some approaches are more easily taught to families and some require strong family commitment<br>5. Not all approaches will work for every patient<br>6. From the array of approaches suggested, the caregiver, based on assessment and understanding of the basis for the symptom, will be able to suggest several alternative approaches<br>VI. Since one is never certain what the life expectancy of any human being is, the approach to symptom management is to work actively to maximize function and minimize the deleterious effects of the symptom within the constraints imposed by an individual patient's condition at the moment. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | VII. The patient and significant others are considered to be the unit of care<br>SECTION B: PAIN<br>I. Pain is produced by an interactive process including physiologic and psychosocial factors<br>A. Physiologic factors:<br>1. Current best theory, due to its practicality, is the Gate Control Theory (Melzack and Wall)<br>a. Large ($A\text{-}\alpha$) fibers carry touch and innocuous sensations<br>b. Small ($A\text{-}\Delta$ and C) fibers carry intense stimulation and burning sensations (pain)<br>c. These fibers enter dorsal horn (SG cells) via dorsal root ganglia and either increase or decrease transmission to the T-cells (which carry the sensation to higher centers)<br>1.a. If the large fiber stimulation outweighs that of the small fibers, the SG cells are inhibited (the gate closes and blocks further transmission of the painful sensation)<br>1.b. If the small fiber stimulation outweighs that of the large fibers the SG cells are stimulated (the gate is opened) and transmission of the painful sensation passes to the T-cells, and crosses over to opposite side of cord and ascends to higher centers<br>1.c. In the thalamus is the area (Central Biasing Mechanism) that acts as a circuit breaker or |

## ALTERNATIVE METHODS OF PAIN CONTROL



| | INTERVENTIONS WHICH "TURN DOWN" EACH SWITCH |
|---|---|
| SWITCH #4--BRAIN (Cerebral cortex) | Narcotics; relaxation; Hypnosis; Tricylcics |
| SWITCH #3--BRAINSTEM (Thalamus) | Narcotics (?); Acupuncture Neurosurgery on hypothalamus and thalamus; Acupuncture |
| SWITCH #2--SPINAL CORD | Neurosurgery on spinal Cord; Electrical Stimulation Massage; Vibration; Heat or Cold |
| SWITCH #1--"Where it Hurts" | Neurosurgery on local Nerves; Local anesthetics; Aspirin and acetaminophen; Heat and Cold; mentholated rub |

Pain exists because an electrical impulse travels along a series of nerves from "where it hurts" through the spinal cord and the brain stem to the areas of the brain where thinking, feeling and action are controlled. Along this path, there are at least four areas where the pain can be switched off. A useful analogy is to imagine these switches as variable controls, like the volume control on the television. Each switch can turn down or turn off the pain. Thus the control of pain can occur because one switch was turned "off" or because a combination of the switches were turned down. Different things affect different switches. So one can use moderate to large amounts of one method (such as medication or surgery) to shut off pain; or one can use small to moderate amounts of a combination of interventions to accomplish the same level of comfort.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

fuse. If too much sensation occurs, it turns the circuit off

1.d. Memory, attention, conditioning and assigned meaning produce stimulation in the cortex which can descend to the area of the dorsal horn and act either like small fiber stimulation or a large fiber stimulation

B. Enkephalins and Endorphins

1. Narcotic substances produced by the body to control sensations

2. High concentrations of enkephalin producing cells in dorsal horn, central biasing mechanism area of thalamus

3. Large fibers may actually be stimulating enkephalin producing cells which release their narcotic and block pain:

    a. By competing for receptor sites on nerve ending

    b. Acetylcholine released by small fiber binds to receptor site causing activation of next nerve cell

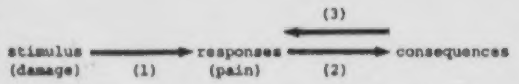
    c. Serotonin secreted by nerves is associated with pain and depression

    d. Enkephalins, narcotics, serotonin compete for the same receptor sites and can block acetylcholine

        1.a. What are nursing ways to effect impulses from being transmitted along pathways

4. Learning effects

    a. Conditioned response begins to occur after only a few hours to days b.


(3)
stimulus (damage)
(1)
responses (pain)
(2)
consequences

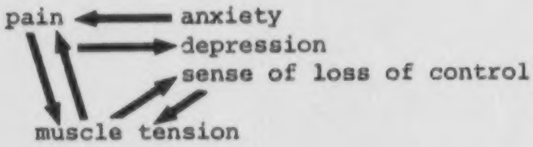
| | | |
|---|---|---|
| body damage | pain | medication/relief |
| | fear, anxiety, | behavior changes-patient/others |
| | depression | failure of system to help, etc. |

c. If this goes on for a long time, it becomes impossible to know how much response is related to factor (1) and how much to factor (3).

C. Psychological Modifiers

1. Memory, meaning of pain can effect gate control mechanism in dorsal horn via descending fibers

2. Secondary gains (behavior changes in patient or others, attention) effect learning of pain response

3. 
pain
anxiety
depression
sense of loss of control
muscle tension

4. Chronic depression is the most common manifestation of chronic pain. Increased muscle tension leads to pain which results in anxiety - is cyclical.

5. Depressed pt. no serotonin, therefore feels pain before others as there is no serotonin to block transference of stimuli

II. Attitudes related to pain

A. Attitude Formation: Three sources aid us in forming attitudes: our own personal experiences, the influence of social sources, our own emotional reactions (Middlebrook, 1973)

B. Specific attitudes toward pain and pain treatment

1. Attitude 1: (most important) health professionals doubt that patients have pain unless they have proven organic basis (Hackett, 1971). Stress no diagnostic test - unable to measure pain

    a. In other areas of heath care there are objective ways of determining presence or absence of abnormality

    b. No test or blood sample can provide us with a diagnosis of pain, or the degree of intensity of someone's pain

    c. In this situation then, the patient is the authority not the health professional; the switch in roles regarding who is in control can be difficult for the practitioner to accept

2. Attitude 2: Health professionals hold on to the idea that they are the authority on whether the patient's pain exists and the degree of its intensity

    a. This attitude/belief can result in an "action tendency" that inhibits accurate assessment, and prevents good pain relief for the patient

    b. An alternative belief/attitude is that pain is a subjective experience and as such is "ultimately defined only by the experiencer" (Sternbach, 1974, p. 2)

    c. Pain is defined according to McCaffery (1972): "Pain is whatever the

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | experiencing person says it is and exists whenever he says it does" (p.8)<br>d. Inherent in this definition is the attitude that the patient with pain is believed (McCaffery, 1979)<br>3. Attitude 3: Health professionals use the acute pain model to evaluate chronic pain (Hackett, 1971)<br>a. This is inappropriate as it results in inadequate assessment of patient with chronic pain<br>b. In acute pain model, physiological signs may be observable: perspiration, increased pulse, increased BP, increased respiration, pallor. Behavior response may include moaning or crying, nausea and vomiting, alterations in pupils, diaphoresis, increased muscle tension and muscle guarding<br>c. In chronic pain, adaptation occurs both physiologically and behaviorally, thus these same signs of pain often do not exist in chronic pain patients (McCaffrey, 1979) Reasons for this:<br>1.a. Physiologically - the responses of autonomic activation can not be maintained forever, physiological adaptation to stress =<br>↓P ↓Bp ↓R<br>1.b. Behavior adaptation in which the patient minimizes his expression of pain can occur for several different reasons: to fulfill the "good patient" role; high personal value on not showing pain; sheer exhaustion from the constant pain; patient may find a way to handle his pain by distracting himself |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | d. With no physiological signs and no behavioral expression it may be incorrectly assumed by health professionals that the patient is not in pain or that the pain has been sufficiently relieved<br>e. Very important to remember when dealing with chronic pain, "a lack of pain expression does not necessarily mean lack of pain" (McCaffery, 1979, p. 13)<br>f. Chronic pain unlikely to see any symptoms nurses have been taught to look for<br>4. Attitude 4: Health professionals tend to reward a high pain tolerance and frown on low pain tolerance<br>a. Some patients have high tolerance for pain<br>1.a. They can endure severe pain without needing relief<br>b. Other patients are not able to endure large amounts of pain and they need relief immediately<br>c. Pain tolerance is defined as what the patient is willing to endure. "Willing" is the key word<br>d. By placing a value judgement on the patient's tolerance, the patient is denied his right to refuse to tolerate pain (McCaffery, 1979)<br>e. Conflict in research, e.g. tolerance, in laboratory everyone's threshold is the same.<br>5. Attitude 5: Health care providers expect patients to respond to pain in ways similar to the provider of care |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | a. Cultural values and beliefs play an important part in forming the individual's patterns of reaction to pain (McMahon and Miller, 1978; Zborowshi, 1969) Nurses attitude from own background should be identified<br>b. Various cultural reaction to pain may conflict with patterns of behavior expected by the American health professional<br>c. Zborowski's classic study (1952)<br>1.a. As their cultures allowed free expressions of feelings, both Italian and Jewish patients exhibited their pain by moaning, groaning and crying<br>1.b. The Jew "tended to mainfest a future oriented anxiety related to the symptomatic and general meaning of the pain experience." (Zborowski, 1952, p. 23) No emphasis on getting rid of cause of the pain<br>1.c. The Italian manifests a present-oriented apprehension related to the actual sensation of pain. (Zborowski, 1952, p. 23) Emphasis on getting rid of the pain<br>d. It is of vital importance in this discussion to avoid stereotyping response to pain according to culture--and to remember there may be many different responses within one culture. To avoid this stereotyping, lecturing about different responses found in different cultures is discouraged |

TIME/MATERIALS

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NOTE TO INSTRUCTOR: DISCUSSION QUESTIONS

The following questions should be discussed by the group following item 5d.

Discussion Questions

1. What past experiences have you had in working with patients from different cultures?

2. Can you identify cultural groups predominant in your specific community?

3. Can you identify resource people within your community to assist the Hospice team in their work with patients and families of different cultures?

4. It is important to recognize the significance of cultural backgrounds when examining attitudes towards pain. And as caregivers, we need to realize that if these attitudes and reactions are different from ours, they merit a special attempt to be understood not to be judged.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | 6. Attitude 6: Patients who watch the clock and ask for medication are addicted<br>a. Definitions:<br>1.a. Addiction: a behavioral pattern in which the person becomes overwhelmingly involved in obtaining and using the drug to attain a feeling of well being. The person uses the drug for non-medical reasons and he is obsessed with obtaining the psychological high it can provide<br>1.b. Drug abuse: a broad term which may apply to any pattern of drug use that deviates from the approved medical and social patterns within a given culture (Jaffe, 1975, p. 284)<br>1.c. Drug tolerance: means that a given dose of a drug produces a decreased effect (McCaffrey, 1979, p. 218). Therefore, increasing doses of a medicine need to be given to obtain the same desired effectiveness. Drug tolerance develops only after repeated administrations of a drug. May first see a decrease in duration of action of the drug followed by an insufficient total analgesic effect<br>1.d. Physical dependence: a physiological state--that may occur after repeated administrations of a drug--in which withdrawal symptoms are evident after the drug is stopped<br>b. Relevant considerations: |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | 1.a. The terms physical dependence and drug tolerance are often incorrectly equated with addiction |
| Transparency | 1.b. As can be seen by the table (transparency) - there are some very important differences:<br>- Addiction is a voluntary behavior involving active "drug seeking"<br>- Drug tolerance and physical dependence are involuntary behaviors involving physiological changes<br>- The presence of drug tolerance or physical dependence does not mean that the patient is addicted |
| | 1.c. Rarely is the clock-watcher exhibiting the behavioral pattern of addiction. Usually the "clock watching" is due to the receiving of inadequate pain relief |
| | 1.d. Important to be careful of labeling patients with a word like addiction without first carefully thinking about its meaning |
| | 7. Attitude 7: Narcotics given regularly around the clock for several days will enhance patient's chances of becoming addicted |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

**NOTE TO INSTRUCTOR: DISCUSSION QUESTIONS**

The following question should be discussed by the group following item 7.

**Discussion Question**

What percentage of hospitalized patients recieving 100 mg meperidine intramuscularly every four hours for 10 days do they think will become addicted?

1. Answer in less than 1 percent in acute care. (Marks & Sacher, 1973)

2. Studies in hospice setting indicate risk is 1-2% even when narcotics are given round the clock for months (Twycross, 1978)

3. Undertreat 99 patients out of 100 because of worry about the 1% who do get addicted.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

8. Attitude 8: Withholding narcotics will help prevent addiciton

   a. This belief may lead to the doctor under prescribing narcotics and the nurse giving the narcotic less frequently than when it is ordered (McCaffery & Hart, 1976; McCaffery 1979)

   b. Fact-Delaying the administration of the pain medicine causes increased suffering, and contributes to a condition of preoccupation and craving for the one thing that can relieve pain - the narcotic (McCaffery, 1979)

      1.a. Likelihood of psychic dependence

      1.b. Learning response

   c. The patient and family may be concerned about addiction

      1.a. Result: patient holding off as long as possible before asking for pain medicine

      1.b. Some ways of dealing with this concern:

      - Ask the patient if there is any reason for which she/he might want to continue taking the narcotic after the pain is gone

      - If the patient can answer no, then explain that he will not become addicted because addiction is a voluntary behavior (no drug will take control of him against his wishes) (McCaffery, 1979, p. 223)

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

9. Attitude 9: When an analgesic is ordered PRN, it should be given only when the pain is severe (Mc Caffery, 1979)

   a. patient experiences significant pain before asking for his medicine and continues to wait in pain until the medicine becomes effective

      - In this cycle the patient may only obtain a few hours of relief before the pain returns
      - The knowledge/experiences with recurrance of pain leads to anxiety which increases the intensity of pain (Mc Caffery, 1979)
      - Enduring pain reduces tolerance to pain and may increase occurance of drug tolerance (Mc Caffery, 1979)
      - Preventative approach: give analgesic PRN at first indication of pain consistently takes less medicines to prevent pain

   b. the previously mentioned belief that around the clock narcotics contribute to addiction may be the reason for our hesitancy to order analgesics on a regular schedule

   c. for prolonged pain that is constant and severe, a regular schedule of analgesics is indicated (Twycross, 1978; Lipman, 1980)

      - By preventing the severe recurrance of pain, the perpetualization of the cycle of the fear of pain leading to anxiety is eliminated
      - Usually less analgesic is required to prevent recurrance of pain than to treat pain after it has recurred (Lipman, 1980)

- The around the clock schedule may not be easily accepted by the patient, family or the health team members (Mc Caffery, 1979)

NOTE TO INSTRUCTOR: DISCUSSION QUESTIONS

The following questions should be discussed by the group following item II.

Discussion question:

1. "Why are attitudes toward pain important to consider?"

   - the attitudes we hold about a topic or subject will influence our behavior towards it (Brooks, 1979; Marlow, 1971).
   - the attitudes we hold about pain will influence our behavior towards our own pain, other people in pain, and our treatment of pain
   - important to be cognizant of the attitudes: of the person experiencing pain, of the family dealing with his pain, and of the health professional managing the pain.

Important to discuss: What an attitude is and how attitudes are formed

- Have three components: a cognitive component, a feeling component, and an action tendency (Freeman, Calsmith, & Sears, 1974)
  - the cognitive component of an attitude consists of the individual's beliefs about the object including an evaluative factor
  - the feeling component of an attitude is concerned with the emotional feelings towards the object

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- Attitudes then can be perceived as a collection of beliefs, feelings and behavior organized around the subject of the attitude (Middlebrook, 1973).

III. Assessment of Pain - Baseline data

  A. Physiologic parameters

    1. Pulse, blood pressure, respirations, muscle tension are not good measures of chronic pain, but do measure side effects of therapies

    2. These do not indicate pain accurately except in acute episode

    3. Best indicators of side effects/accuracy of dose

  B. Verbalizations (Patient is authority)

    1. Location

      a. Ask patient to point with one finger to area of pain, if patient can point to or circle with one finger can use gate control mechanism; if area is larger more diffuse gate control mechanisms are not good interventions

      b. If able to localize, pain is superficial and limited, suggesting use of interventions to use the gate mechanism

      c. If unable to localize, pain is deep, visceral and/or less likely to be successfully located and verbalized

    2. Quantity

      a. Ask "If 0 is no pain at all and 10 is the worst pain you can imagine, how much pain do you have right now?"

b. "How much pain is left when you ____________________?"
(pain relief measure)

c. "How bad does the pain get at its worst?"

3. Chronology

    a. Area of pain increases with duration of pain

    b. To intervene early it helps to be able to identify first signs of pain

    c. Some patients can identify a pre-pain experience: e.g., legs feel heavy before pelvic pain starts

4. What factors aggravate the pain?

    a. Activities

    b. Sitting positions

    c. Interactions

    d. Procedures

C. Vocalizations

1. In pain (out of control), the patient may be unable to answer questions

2. Measure of progress can be number of hours/day, moaning/crying or loudness of moaning/crying

D. Facial expression/thrashing - unlikely with patients with chronic pain

1. Only measures acute pain in certain individuals

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2. Many people, even in acute pain, have learned to lie as still as possible and try to relax

3. Many patients in chronic pain have learned grimaces and thrashing don't help

4. Patients in chronic pain often immobile, have a flat affect, appear depressed and lethargic

5. Interactions with others

    a. In mild-moderate pain, interactions may increase to utilize distraction-Auditory input; example music

    b. In severe pain, interaction is often severely limited so overwhelming can't focus on anything else

    c. Depression often causes reduced interaction

    d. Some people benefit from interactions far more than others

6. Patterns of handling stress in the past

    a. What has worked?

    b. What hasn't worked?

    c. What does patient think would help?

    d. Also, asking these questions increases number of interventions nurse knows

7. Mini-pain assessment (Thorough pain assessment takes three hours)

    a. P - Place (location)

## ASSESSMENT OF THE PAIN EXPERIENCE

| PARAMETERS | COMMENTS |
|---|---|
| I. Signs of stress<br>Vital signs: BP,P,R<br>Diaphousis<br>Nausea | It is important to consider the chronicity of the pain and the possibility that the stress response may have been exhausted yielding signs of parasympathetic stimulation (l P, l BP, l R, warm skin) rather than signs of sympathetic stimulation (l P, l BP, l R, cold and clammy). |
| Muscle tension | Assess by observation and by asking patients if they are aware of any tight, tense muscles. Approximately 50% of individuals asked by the author to identify muscles which were tense could not do so until after they had been taught a systematic relaxation technique. |
| II. General observations<br>Posture<br>Facial expression | In acute pain, frequent postural changes and facial grimaces are common in some individuals (usually culturally based). However, in the case of the chronic pain, postures characteristic of withdrawal and lack of facial expression are more characteristic. |
| III. Characteristics of pain location | Asking the patient to outline the pain with one finger not only describes location but also begins to suggest the appropriateness of certain interventions, since localized pain will respond to interventions which stimulate the SG - T-cell gate and diffuse pain will not. |
| Duration | How long has the patient been experiencing pain? What are the patterns of pain and relief from pain? |
| Quantity | Asking the patient to estimate the amount of pain being experienced right now (on a scale where 0 = no pain and 10 = the worst pain you can imagine) allows for greater consistency in |

| PARAMETERS | COMMENTS |
|---|---|
| | charting, a clearer understanding of the patient's experience and is a method of evaluating the effectiveness of interventions (numerical change). It can also be helpful to ask, "On that same 0-10 scale, how much pain do you have when it is at its least?" "How much pain do you have when it gets to be its worst?" |
| Chronology | For some patients, a pattern of how the pain develops and progresses can be identified. Interventions early in this process will often be far more effective than interventions employed after the pain is well established. |
| Aggravating factors | What events, timing, people, behaviors, activities, etc. make the pain occur or intensify? |
| IV. Methods of relief | What has been used in the past? When was it used? Duration of use? What is currently being used should be apparent from the chart. It is important to verify the use of current orders and their effectiveness with the patient. (For example, a dorsal column stimulator which is kept in a drawer or Percodan which is taken only every 6-8 hours cannot be discounted as ineffective.) |
| V. Interactions with others | How does the patient act when he is in pain? Observe, ask patient, ask family member(s). How do significant others and health caregivers act when the patient is in pain? How do significant others and caregivers act when the patient is not in pain? What does the patient do when not in pain? |
| VI. Previous response to stressful situations | A patient who has responded by learning about various solutions and trying alternatives will respond better to different approaches than the patient who turns to others for solutions, |

| PARAMETERS | COMMENTS |
|---|---|
|  | who withdraws or "falls apart," or who "just waits it out." |
| VII. Goals | What would the patient like to be doing right now, this week, this month if the pain was better controlled? How much would the pain have to decrease (on the 0-10 scale) for the patient to begin to accomplish these goals? |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

b. A - Amount (0-10)

c. I - Interactions (aggravating factors, relationships)

d. N - Neutralizers (what helps?)

MINI-ASSESSMENT OF PAIN

| | |
|---|---|
| P - PLACE | Ask the participant to outline the pain with one finger. Is there a pattern of progression of the pain (chronology)? What is it? Where does it start? Where does it go? Does it change in this process? |
| A - Amount | 0 = no pain; 10 = worst pain you can imagine. "How much pain do you have right now?" "When the pain is at its worst how much pain do you have?" |
| I - Interactions | What does patient do when in pain? What makes pain worse? What do others do when patient is in pain? |
| N - Neutralizers Are the interactions which help | What helps relieve the pain? How effective is it? (0-10 scale) What has been helpful in the past? |

IV. Interventions to Modify the Pain Experience

   A. Non-invasive pain relief techniques

      1. Rationale and overview

         a. Usually are low risk, mild, and have few side effects

         b. A physician's order may be required, and physician involvement is always

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

advised

c. Family involvement is essential. Inform them of the technique, its effect upon pain and the situation for which it is useful. They can be quite encouraging to the patient

d. Ideally, the technique should be taught to the patient when pain is mild or absent. Practice sessions should be scheduled prior to when it is needed

e. The technique can still be taught when patient is in pain. The patient may prove to be more motivated but the ability to concentrate will be decreased

f. The nurse should perform the technique along with the patient to deter any embarrassment the patient might be feeling (when not in pain) and to assist in concentration (when in pain)

NOTE TO THE INSTRUCTOR

The following should be discussed after item IVf.

Process for group discussion: The techniques discussed in this module are non-traditional. Patients are accustomed to the offering of medication for their pain. Thus, they may react to the nurse's suggestion in a negative manner.

- Discuss possible reactions to these non-traditional techniques both on behalf of the patient and the students themselves. Consider that some pain is not amenable to medication alone

- Discuss the impact the nurse-patient relationship has upon the patient's confidence and willingness to experiment. How does the presence of trust and concern impact upon pain

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Students need to practice these techniques (either in class or lab or as homework). A student's comfort with a technique strongly influences the utilization of that technique.

2. Cutaneous Stimulation

   a. General Description

      1. Techniques that stimulate the patient's skin to relieve pain

      2. Appropriate for many types of pain: acute to chronic, mild to severe

   b. Mechanism of action is not fully understood-probably increase release of endorphine and enkephalens

      1. Gate Control Theory

         - May activate peripheral nerve endings (large fibers)

         - Stimulation of afferent nerve fibers mask or modify the perception of pain

         - Partially block noxious input (SG-T-cell transfer)

      2. May increase endorphin production/release

      3. May increase blood supply and muscle relaxation

   c. Location: test multiple sites until most effective are found for individual patient

      1. Melzack (1975) suggests 3 areas:

         - Trigger zones - best place to start

palpate the painful area to find the area that provokes the most pain: body, head, chest, pelvis and extremities

- Peripheral nerve routes: if no trigger zones can be located
- Acupuncture points: Kao and Kao (1973) or Mann (1966). Depends on the diagnosis and the pain pattern

2. Contralateral stimulation indicated when a painful area is too sensitive to be stimulated directly or in phantom pain if a, b, and c don't work. Use opposite side from where pain is experienced.
3. Sometimes stimulation of unrelated areas of the body provide relief (Carter, 1975, Ingham, 1963) if other areas of body stimulation don't work

d. Amount

1. Always begin with a moderate amount. Controversy over amount. Use amount that doesn't hurt.
2. Minimal stimulation may be effective or amount of stimulation required to produce best results may be as great as just below the intensity that resulted in pain (Melzack, 1975)
3. If relief of pain results only during stimulation, a continuous stimulation is appropriate, (heat, or menthol product, TENS)

### GUIDELINES FOR DEVELOPING AND USING CUTANEOUS* STIMULATION

1. Combine a trial-and-error approach with common sense, allowing the patient's perception of

*Reprint with permission: J.B. Lippincott Co. McCaffrey, M. Nursing Management of the Patient in Pain; Phil Lippincott, 1979 p. 136.

TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE

relief or no relief to be the ultimate guide

2. Select one or more specific methods of cutaneous stimulation from the following categories for the purpose of experimentation:

   a. pressure
   b. massage
   c. vibration
   d. heat
   e. cold
   f. external analgesics, e.g., menthol preparations
   g. transcutaneous electric nerve stimulation (TENS)

3. In selecting the above methods, consider the following:

   a. convenience, e.g., availability, ease of use, administered by patient or others, time involved
   b. cost
   c. precautions and contraindications related to each method

4. The intensity of cutaneous stimulation usually is moderate. (For an acute injury only mild stimulation may be advisable.) If intense stimulation is required for pain relief, the intensity should be just below the level that the patient perceives as painful.

5. Frequency and duration of stimulation ideally is determined by how long pain persists following stimulation. Some patients require continuous stimulation for continuous pain relief. Other patients experience relief for minutes or hours following stimulation.

6. In applying cutaneous stimulation, those areas of the body that may be considered are:

   a. skin over or near the pain site
   b. trigger points
   c. acupuncture points

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d. peripheral nerves
e. contralateral site
f. areas unrelated to the pain site

(McCaffrey, M. 1979, p. 136)

g. Other Techniques

1. Heat: Question of dry or moist; differs with patients.
   a. physiological effects in addition to effects on gating mechanism:
      - Increases blood flow; increases edema; decreases joint stiffness and reduces muscle spasm or tension
      - Effects may be enhanced by passive range of motion
   b. methods of use:
      - Dry heat: rubber hot water bottle heating pad, exposure to electric light bulb, for 30 minutes (not a sun lamp)
      - Moist heat: 1) showering or bathing with hot water; 2) moist heat pack filled with silica gel; 3) wrap part in plastic 4) saran wrap
2. Cold: May relieve pain longer than heat; varies with individual
   a. Physiological effects in addition to effects on gating mechanism:
      - Decreases blood flow, decreased inflammatory response, decreased edema and increased joint stiffness
   b. Methods of use:

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|---|---|

- Towels soaked in ice water; ice bag; reusable gel pak
- Make a popsicle, using water frozen in a paper cup with tongue depressor for handle. Using slow even strokes, gently massage area of pain (10 minutes)
- Effects may be enhanced by passive range of motion
- Discontinue if shivering or muscle spasm occurs

3. Massage

Purpose: Stimulate circulation; close gate by stimulating large fibers, relax patients

Methods:

a. Use powder or mineral oil (so it gets absorbed)

b. Begin with long even strokes and progress to kneading motion

c. Wash residue off skin

d. Teach family or significant others

e. Utilize prescription format to enhance acceptance. Write out a prescription blank

4. Vibration (Donovan, 1980)

a. Utilize prescription format to enhance acceptance

b. Write out procedure in detail for individual

- location, duration of stimulation

- use of lotion or powder

5. Transcutaneous Stimulation (TENS)

   a. Noninvasive pain relief measure consisting of cutaneous stimulation

   - The stimulation is a mild electric current applied to the skin via electrodes
     - 2-4 or more electrodes connected by lead wires to a stimulator
     - Adjust knobs on machine to produce sensation that relieves pain
     - If muscle contraction occurs, the intensity of the current is reduced
     - Some units are designed to be used at subsensation levels; when sensation is felt, the stimulator is turned down to just below sensation level
   - Need physician's prescription

   b. Types of stimulators:

   - Differ in many ways: durability, weight, number of control knobs, waveforms, amplitude, rate and pulse width, size and shape, or conductive gel types

   c. Actual use of the TENS

   - Find optimal site for stimulation
   - Adjust rate until patient expresses a preference from a thump to a mild tingle at the electrode site
   - Adjust pulse width
     - As pulse width increases, output is

decreased until maximum pain relief is felt

- frequency and duration of stimulation
    - May be continuous or intermittent: electrodes can be detached from unit and remain in place until stimulator is again needed
    - 10-30 minutes is most commonly reported duration for intermittent, determined by how long pain relief persists. Stimulation reapplied when pain returns
    - If patients need continuous stimulation and are active people, a small clip-on stimulator can be carried and concealed in a pocket or attached to a belt. Turn off for one hour every six hours to decrease skin reaction
- patients can learn to apply and adjust them independently
- warn patient not to remove electrodes before the apparatus is switched off; may get a sudden electric shock due to sudden increase in output

d. Side Effects of TENS

- Skin reactions
    - Usually when electrodes worn for long periods consistently
    - Change to a hypoallergenic tape or belts, elastic and velcro strips, or elastic bandages, change to a stimulator with a symmetrical bipolar wave form

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Treatment
  - Clean both skin and electrodes with soap and water at least once a day
  - Rotate electrode sites to allow for healing
  - Cortisone cream
- Contraindications for use of TENS: patients with cardiac pacemakers; history of myocardial infarctions or arrhythmias; indications of thrombophlebitis

6. Therapeutic Touch

a. Technique involves placement of hands on or near the patient for 10-15 minutes

b. Research showed that healer must have a strong desire to help or heal while touching for technique to be effective. Patient's faith in the efficacy of the technique proved not significant (Krieger, 1975)

c. During the laying on of hands, the patient has a subjective sense of heat in the area being touched (Krieger, 1975, p. 786)

7. Distraction:

a. It is the process by which the patient's attention is diverted from pain and onto other sensations

- The ability of a patient to be distracted from pain, either by a phone call, visit from a friend or an exciting ballgame, does not suggest the absence of pain. Patients experiencing moderate (4-7) pain are most receptive to distraction
- Powerful distractions for the patient should be identified and, if scheduled

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | ahead of time, can be incorporated into the plan of care for pain<br>• Mechanism of action may include altered perceptions and overloading central biasing mechanism<br>• More senses involved the more likely it will work<br>- Humor<br>- Breathing<br>- Music<br>- Visitors<br>- Environmental distractors as mobiles, pictures<br>- Games<br>b. Effectiveness/Limitations<br>• Most effective with intense pain of brief duration<br>• Usually, patients who have used distraction previously (and many have) will again find distraction to be quite effective<br>• The effects of distraction are usually felt only for the time the patient is distracted<br>• Following distraction, patients often are fatigued and are increasingly aware of the pain. Thus, the time after the distraction period needs to be planned for<br>• Match the intensity of the pain with complexity of the distraction (mild - simple distraction; moderate - more complex disdistraction; severe - less complex distraction)<br>• Utilize as many of the five senses as possible (see, hear, touch, feel, smell); the more active the patient's participation, the better the distraction, |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

i.e., playing a game is more of a distraction than reading, T.V.-passive, crossword puzzles-more active, play checkers with someone else.

- Most importantly, consider the patient's interests

c. Types of distraction:

- Rhythmic breathing techniques

NOTE TO INSTRUCTOR

Discussion Exercise

Facilitator shall demonstrate the He-Who Rhythmic Breathing distraction strategy for the class. Then have the class split up into pairs: one be the nurse, the other be the patient, to perform the he-who technique.

HANDOUT

He-Who Rhythmic Breathing.* This distraction strategy involves the following:

1. The patient takes a slow, deep breath at the beginning of using this technique and again when he is through. He should also feel free to stop and take a deep breath whenever he feels the need.
2. The rhythm is maintained by the patient whispering "he" upon exhalation, inhaling again and then whispering "who" upon exhalation. This rhythm is repeated over and over. No sound is made upon inhalation. Each whispered word represents the completion of a complete breath. Thus, the nurse's instructions while she is coaching the patient might be "Inhale, he, inhale, who, inhale, he, inhale, who..." Exhalation should remain passive. Caution the patient not to force exhalation as he whispers the words and not to prolong the

*Reprint with permission: J.B. Lippincott Co., McCaffrey, M. Nursing Management of the Patient in Pain, Phil Lippincott, 1979, pp. 105-106.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | sound of the words. Children usually are simply allowed to speak the words out loud. Currently, most nurses who have worked with this distraction strategy seem to prefer the words he-who, but other words may be used, such as ha-who. Patients often substitute "hee-haw" or "haw-haw," as if trying to make a joke of the pain.<br>3. The rate of this rhythmic breathing begins slowly and the rate increases as pain increases in intensity. The rate probably should not exceed 60 breaths per minute. The rate decreases as pain decreases. He-who breathing stops when the pain stops or when it reaches a more tolerable level.<br>4. Breathing is done through the mouth since it is usually difficult to breathe rapidly through the nose.<br>5. Breathing must be shallow chest breathing since the rate may become rapid. Fatigue and other complications may result if the patient takes deep, rapid abdominal breaths. The patient may be taught what a shallow breath is. Instruct him to open his mouth and inhale slowly, noting, the proper depth of inhalation when he feels a cool sensation in his throat.<br>6. Any of several quick and simple motions, noted in previous breathing techniques, may be coordinated with inhaling and exhaling to increase the complexity of this distractor. The head may nod up and down for inhalation and exhalation repectively, or a finger may be raised and lowered. Also, the head may be turned to the right or left side to whisper "he" and to the front to whisper "who." This causes some dizziness, especially if the breathing becomes rapid; however, the |

lowered level of consciousness is viewed as an advantage by some patients.

7. Several types of visual stimulation are possible. A concentration point may be used. The patient who turns his head from side to front simply may keep his eyes open, or he may choose two concentration points, one to the side and one in front. Another possibility is conjuring up mental pictures or imagery. The words he-who sound very much like the old fashioned locomotive or "choo-choo" train. Therefore, it may be easy for the patient to close his eyes and picture a train, seeing himself boarding the train as soon as the pain begins or before the pain begins. To make the train go faster to escape the pain, he can increase the rate of breathing and at the same time he can picture the train gathering speed. The breathing rate and the train slow down as the pain decreases in intensity.

8. Rhythmic massage may be added to increase the complexity of the distractor. In fact, children and some adults may be agreeable to coordinating massage with the image of the train. Both hands can be used to rub both hips in a circular fasion, like the wheels of the train. The circular motion can increase in speed along with the increasing rate of breathing and the increasing speed of the train.

As stated, either he-who rhythmic breathing or pant-blow may be used for pain of severe to very severe intensity that tends to wax and wane in intensity within a matter of seconds. It is my impression that, compared with pant-blow, most adults and children find he-who breathing easier to learn and that most nurses are able to explain and demonstrate it more quickly.

(McCaffrey, M. 1979, 105-6)

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Music
  - Is especially good when earphones fitted with large muffs are utilized. This technique can then be made more complex by body movements coordinated with the the rhythm and/or rhythmic breathing
  - Adjusting the volume to match the intensity of pain enhances the technique
  - Consider also recording comedy routines or a sport event
  - Strong beat and/or rhythm works best
- Humor
  - Norman Cousins (1976) has described from personal experience how a deep laugh at humor books or clips from Candid Camera resulted in 2 hours of pain relief. He recommends two books in particular: E. B. and Katherine White's Subtreasury of American Humor (1941), and Max Eastman's The Enjoyment of Laughter (1936)
- Distracting Environment
  - Maintaining a stimulating environment that matches the patient's previous level of sensory input is essential
  - An occupational therapist and physical therapist can be very helpful in devising exercises and interesting activities. Helping the patient plan each day hour by hour could be quite helpful
  - Help the patient discover not only activities that will be enjoyable but also those that will create a sense of achievement. Both can enhance the patient's self-esteem and will preserve the quality of life

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

d. Relaxation

- It is a state whereby both muscle tension and anxiety are eliminated
    - Sleep state is not necessarily a relaxed one. Dreams may create tension; it is also possible to fall asleep with muscles tense
    - Even when muscles aren't being used, as in reading a book, watching television, they are not necessarily relaxed. They can be resting without being relaxed
    - We all commonly think we are relaxed when we are not. Thus, we could all learn how to relax. This is a skill

e. Think of pain as one type of stressor. Think of the patient as responding to this stressor in an intense problem-solving manner, attempting to master the stressor. Patients are so engrossed that they stop perceiving the feedback from the body telling of muscle tension. This then results in chronic muscle tension producing increased pain

f. Elements of a Relaxation Response

- Benson (1975) identified four: quiet environment, comfortable position, mental device (focus), positive attitude

Preparation Phase

| Objective | Methods of Attainment |
|---|---|
| Realistic expectations | Discuss goals; set interim goals. Stress skill development. Identify sensory cues. Instruct significant others as well |
| Enhancing environment | |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

| | |
|---|---|
| Minimum distractions | Reduce glaring light. Close curtains, position learner so she/he is not facing light, use low wattage light, closing eyes may help<br>Decrease interruptions; place sign on door; let everyone know; choose place wisely; use background sound such as radio or tape to mask intermittent noise; sit close enough to be heard but not so close as to be intrusive. |
| Comfort | Recliner chair, bed or couch is best. Be sure all body parts will be well supported as they relax (check head, arms, back, legs). A light blanket may be needed by those who feel cooler as they relax (Donovan, 1980). |

9. Imagery

a. Imagery refers to the patient using imagination for the creation of images that relieve or decrease pain

- Provides internally controlled distraction
- Results in physiological changes including deep relaxation (Jacobson, 1967)
- Most useful images for pain relief draw upon all five of the senses: taste, hear, smell, see, and feel

b. Technique is appropriate with patients experiencing chronic pain and those with

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

spasmodic pain that is typically difficult to treat with medication. Patients must be able to concentrate for technique to work (Donovan & Pierce, 1976)

- Usual length of time for effect is 10-20 minutes while waiting for medicines to take effect

c. Types of Imagery:

- Standardized Images

  - Specific images that have been developed for relief of pain. Typically, they are read to the patient or recorded on a tape recorder. Standardized images can be altered to suit the patient. Are convenient and time saving. Limitation: no image fits all patients. May be distressing not relaxing.

  Beach Scene.* You are walking along the beach; it is mid-July. It is very, very warm. It is five o'clock in the afternoon. The sun has not yet begun to set but it is getting low on the horizon. The sun is a golden blazing yellow, the sky a brilliant blue, the sand a dazzling glistening white in the sunlight. Feel the cold, wet, firm, hard-packed sand beneath your feet..taste and smell the salt in the air. There is a residue of salt deposited on your lips from the ocean spray. You can taste it if you lick your lips. Hear the beating of the waves the rhythmic clapping to and fro, back and forth of the water against the shore. Hear the far-off cry of a distant gull as you continue to walk...

*Reprint by permission: J.B. Lippincott Co. Krogie, W.S. and Fezler, W.D., Hypnosis and Behavior Modification: Imagery Conditioning. Phila: Lippincott, 1976.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Suddenly you come to a sand dune, a mound of pure white sand...Covering the mound are bright yellow buttercups, deep pink moss roses. You sit down on its crest and look out to sea. The sea is like a mirror of silver reflecting the sun's rays, a mass of pure white light, and you are gazing intently into this light. As you continue to stare into the sun's reflection off the water you begin to see flecks of violet, darting spots of purple intermingled with silver. Everywhere there is silver and violet. There is a violet line along the horizon...a violet halo around the flowers. Now the sun is beginning to set. With each movement, with each motion of the sun into the sea you become deeper and deeper relaxed. (It is important to pair physical sensations such as breathing with elements in the image so that the imaginal elements will cue relaxation). The sky is turning crimson, scarlet, pink, amber, gold, orange as the sun sets...you are engulfed in a deep purple twilight, a velvety blue haze. ...you look up to the night sky. It is a brilliant starry night. The beating of the waves, the smell and taste of the salt, the sea, the sky,...and you feel yourself carried upward and outward into space, one with the universe...I am now going to count to 3. At the count of 3, you will open your eyes, you will feel completely refreshed, totally relaxed. 1,2,3.<br>(The subject is always brought out of hypnosis by reciting the above three lines)<br>The last two lines in this image should produce a feeling of detachment and often dissociation.<br>(McCaffrey, 1979) |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Self-designed image
  - Patient describes own image
  - Write it down or record it for future use
  - Overcomes some limitations of standard images
  - Make own personal tape; if nurse busy tape is available
- Relaxation with Guided Imagery (RGI)
  - Capitalizes on both relaxation and self-designed imagery
  - Assessment is essential
  - Profound deep relaxation not used more than three times/day. More than this patient becomes disoriented.

Pretraining Assessment

| | |
|---|---|
| Reason for learning RGI | Why are you interested in learning a systematic relaxation technique? What do you expect to gain from learning RGI? Have you ever used a similar technique (yoga, TM, prepared childbirth)? What is the effect of that technique? |
| Areas of tension | When you are tense, worried, or upset, where do you feel it? What areas of your body tell you that you are tense? What does it feel like? If 0 represented complete relaxation and 10 as tense as you could be, how tense are you right now? |

## THE PHASE OF IMPLEMENTATION

Reprint with permission: Masson Publishing USA, Inc. - Donavan, M. "Relaxation with Guided Imagery: A Useful Nursing Skill," Cancer Nursing, 1980, 3, pp. 27-32.

Spend a few moments now being certain that you are in as comfortable a position as possible...[a]Arms at your sides...Legs uncrossed...[b] Head supported comfortably... Move around a bit if you wish so that you are comfortable...As comfortable as you can get right now...You may find it less distracting at this time if you close your eyes. Or you may continue to focus on __________[c].

Take a deep breath.[d] Let it out slowly. ..Think relax...Take another deep breath. Right.[e] Let it out very slowly. ...Think relax...You may notice already that your body is starting to calm itself. There are muscles all over your body that hold tension.[f] You have the ability to learn to recognize that tension and to get rid of it...To learn the skill of relaxing.[g]

To help you to begin to identify the tension...and then to relax...it is useful for you to focus on the various parts of your body...to focus on them and to notice any tension that may be there...and then to relax each part in turn. It is easiest for most people[h] to begin with the hands ...Think about your hand...one hand or both ..Notice how it feels...Now make a fist. A tight hard fist! Notice the tension in your hand. The next time you exhale, let the fist relax...Good! Now notice the differences...the feelings that mean relaxation to you. They may be feelings of warmth...or coolness...or heaviness... or lightness...or other changes in sensation. Whatever these sensations are, they are your signals that the muscles are relaxing.[k]

[a] Speak slowly and calmly in rhythm with the person's breathing

[b] As muscles relax, it is easier to compress blood vessels or nerves

[c] Point out a small area directly in person's line of vision

[d] If individual has a history of respiratory problems, you will probably skip this section

[e] Praise the ability to accomplish the steps where appropriate

[f] Do not rush. Give the person time to fol the coaching

[g] Important to stress that this is skill to learn and practice

[h] If the person has learned a technique that starts with head or feet, it is usually better to follow their original progression

[i] Periodically reinforce that the person is doing well

[j] After you have finished this training, you can ask the person what sensations seemed to accompany relaxation and use these next time

[k] If the hands are an area of tension, you may repeat this specifically with the other hand

Now focus on your forearms...Notice any tension there...Relax them...Just allow yourself to relax more and more...Focus on your upper arms...Relax them. Allow both arms and hands to relax...Allow your special feelings of special relaxation to spread from your fingers and hands through all of the muscles of your arms...You may be surprised that even when your muscles seem to be relaxed that you can learn to relax them more and more.

Now focus on your forehead and scalp...any tension there. Imagine[l] the tension being wiped away with a soft, soothing, warm cloth...Take the time to feel the tension being wiped away...Imagine the tension in the muscles around your eyes... tight little lines of tension...Let the relaxing feelings spread down from your scalp and forehead...down over and around your eyes...Notice any tension in the muscles of your cheeks...your jaw...your mouth and tongue...Tell these muscles to relax...Opening your mouth very wide[m] and then relaxing your jaw can help the tension flow away...Fine!...Let the feelings of comfort that started in your hands flow through all of the muscles of your face... Soothing...relaxing...calming.

Notice any tension in the muscles of your neck...[n] It is sometimes helpful to imagine this tension as knots in heavy ropes...You can mentally untie those knots ...Imagine yourself slowly...and persistently untying the knotted muscles...One by one...As you do so, the muscles can become more and more relaxed.[o] If not all of the tension is gone, that's okay... More tension will continue to disappear as you become more skillful with practice and as you progress from muscle group to muscle group.[p]

[l] Imagery may be used wherever it is helpful to simulating relaxation. Or you may continue to use the focus on the tension and release it as was done with the hands and arms

[m] This is an area of tension for many, the extra time may be needed

[n] For those who have much tension here but have difficulty relaxing, it is helpful to have them push their heads back against the chair or bed, tensing these muscles and then relaxing quickly

[o] This image like all images may be appropriate for some but not for all

[p] Reinforce that it is a skill that needs practice

[q] Even when other references to breathing have been eliminated this can be useful

[r] This is the introduction to the short technique which can be used anywhere. See note x

## THE PHASE OF IMPLEMENTATION

Now focus your attention on your shoulders and upper back...Just allow those muscles to relax...Notice any tension...any heaviness or tightness in your chest... Each time you inhale, feel those sensations[q] that mean relaxation to you moving through more and more of your body...And each time you exhale, feel the tension flowing out of your body...Just blow the tension away.[r]

The muscles of your abdomen...Relax them... The muscles of your lower back. Those long muscles extending from your buttocks right up to your shoulders...Relax them.[s]

Focus on the muscles of your legs...Your[t] buttocks. Thighs. Calfs, Ankles. Feet Then let them relax.

Just let the ______support your legs. Let them relax...Feel those sensations you have come to recognize as meaning relaxation for you. Feel them moving from muscle to muscle. Let your thighs relax... your calfs, relax...your ankles and toes relax...[u]

While you are relaxing the muscles of your body it can be even more comfortable to be able to enjoy that special image we talked about so that you can relax your mind as well...Begin by imagining that very special phase...experience it as vividly as if you were there...[v]

Notice how calm[w] and relaxed you have been able to get. Remember that relaxation is a skill and will increase as you practice. Throughout the day, whenever you notice that you are tense or upset[x]...Take a deep breath...Hold it for the count of three...Then exhale and blow[y] away the tension and think R-E-L-A-X. Take a deep breath...Hold it for the count of three... Then exhale and think R-E-L-A-X.

[s] If either of these is an area of tension, far more emphasis will be needed and they would be done separately

[t] Same as note s

[u] If the person seems to be having much troub relaxing, you can quickly go through the body once again. For example, "Focus on each group of muscles once again and release any additional tension you find there... Arms...Relax Head and Face...Relax...Neck... Relax...Back...Relax...Abdomen...Relax... Legs...Relax."

[v] Facilitate the experience of the image by orienting all of the senses: the overall experience, sight, smell, hearing, touch, taste, emotional reaction. For a detail-oriented person, use many details. For a less detail-oriented person, general impressions are better.

[w] Meant to give person chance to evaluate the degree of effect each time

[x] Short technique

[y] Exhale slow and say R-E-L-A-X as you do so

[z] Emphasize NOW

[aa] It can take 2-120 seconds for an individual to think backwards and become more alert depending on how relaxed he/she was.

## THE PHASE OF IMPLEMENTATION

To begin to experience more muscle tone returning and to become more alert, begin to think the numbers backwards from 4 to 1. Allow just a bit more muscle tone to return with each number. You may want to begin by moving your feet and legs and then more and more of your body as you now think backwards from 4 to 1.

See previous page.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | Medical/Psychiatric contraindications: Are you currently taking any prescription medication? What? Have you any history of heart irregularities, respiratory problems, depression, psychosis? Do you have any joint or back problems? Do you wear contact lenses?<br>● Relaxing image: Describe for me a place you would really like to be that is extremely relaxing and refreshing. What would you see? Hear? Taste? Smell? Are you alone? Who else is there? What are they doing? How do you feel? (Donovan, 1980)<br>- Phase of implementing the technique (Donovan, 1980)<br>10. Hypnosis<br>● Hypnosis has been used for relief of pain for centuries and has been found to be quite successful. Evidence suggests that when in a hypnotic state, control systems in the mind shift resulting in a modification of the perception of pain (Hilgard, 1973)<br>- Most everyone can experience some degree of hypnosis. In normal individuals, there is no threat of the hypnotic state persisting indefinitely. The normal subject cannot be induced to violate his own code of behavior. Should a violating suggestion be made, the subject usually awakens spontaneously<br>- Patients with organic pain make excellent subjects for hypnosis usually because they are highly motivated by their desire for relief<br>- Hypnosis coupled with imagery has been found to be quite effective. First the patient is hypnotized and then is directed to image a very pleasurable experience (Jacox, 1977) |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- For further information refer first to Barber, 1978

11. Biofeedback

    a. Theoretical basis

    - Mind and body function as one

      stress → sympathetic stimulation → muscle tension

      One can learn to control this

    b. Goals: Increased awareness of relevant physiologic functions; control over these; and transfer of control from training area to other areas

    c. Procedure

    - Initial interview and briefing

      - Establish therapeutic relationship access attitude of client toward treatment reassure about fears; teach rationale provide individualized information if under physician or psychotherapists care, check first

      - Provide visual and/or auditory feedback -

        - Sensor is attached to client in appropriate manner to measure heart rate, blood pressure, galvanic skin response (GSR) or most commonly muscle tension;

        - Also it is attached to signal-buzzer, bell or light source

        - Relaxation training begins, as client is successful in reducing tension, pulse,

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Blood pressure when below a certain predetermined number the signal changes to provide immediate feedback
    - Patient also practices with tape recording at home without signal for feedback
    - Progression may be made to controlling other parts of body, controlling tension under various conditions, etc.
    - Gradually individual receives less feedback (signal) and is expected to operate on internal feedback (feelings of relaxation, etc).

12. Use of Medications

    a. Effective Use of Analgesics

    - ● Two Classes of Analgesics
        - Non-Narcotics act primarily at peripheral level
            - ● Start with non-narcotics if pain is mild to moderate (0-5 on scale)
                - Single optimum dose 650-1000 mg of aspirin or acetaminophen
                - Average adult can tolerate 8-12 tablet/day (325 mg per tab)
                - Liquid form absorbed faster - dissolve 2 tablets in 2 tsp of warm water and 1 tsp antacid (Mc Caffery)
                - Rectal suppositories not well absorbed
                - Fewer side effects than narcotics:

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

No constipation, sedation, or respiratory depression

- Educate public regarding strong potency of non-narcotics for pain relief

  EXAMPLE (See Equianalgesic List)
  Demerol 50 po = aspirin 650 mg
  Talwin 30 po = aspirin 650 mg
  Codeine 32 po ≅ aspirin 650 mg

- Narcotics action at level of CNS
  - Given with non-narcotics, attack pain at two different levels
  - Double blind study with cancer patients found ASA 600 mg PO with MS 10 mg IM gave significantly greater relief than MS alone
  - Amounts of aspirin or Tylenol in oral narcotic compounds usually is inadequate
    - Consider Empirin #3 or #4 with two additional aspirin or Tylenol, for example

6. Timing

- Give medications on a schedule rather than prn since they are most effective if given before the pain occurs or becomes severe. Use preventive approach
- PRN reinforces pain behavior (learned pain); i.e., when in pain it is necessary to get medications in order to feel better
- PRN puts the patient in the dependent position of having to request medication after the pain has occurred.

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

- Give medication on schedule not contingent on the painful experience
  - Consider each patient's individual response
  - Have patient draw up own time schedule
- Anxiety about pain increases perception of pain; anticipatory anxiety is perpetuated by PRN medication
- There is no hierarchy of narcotics; just that one is better for a certain individual than another

c. Route

1. Oral route preferred
   - Psychologically better for the patient. Patient has more control and is not depending on someone for injections
   - Can maintain adequate drug levels in body using oral route
   - Methadone or Levodromoran are drugs of choice for oral use because of their long duration of action (6-12 hours)
     - Advantages of methadone: well absorbed from GI tract; relieves severe pain (5-10); less expensive; less nausea and vomiting; less sedation and euphoria
   - Morphine sulfate is commonly believed to be a poor drug when used orally. This is largely untrue
     - ½-2/3 of oral morphine sulfate reaches the blood stream. Doses must be adjusted; e.g., MS 15 mg PO equals MS 10 mg IM

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

  - Dr. Cicely Saunders (pioneer in hospice care) now advocates the use of aqueous solution of morphine only as the narcotic of choice for terminal patients (Lipman, 1980)

- If patients have trouble swallowing, try oral liquids. Dissolving morphine sulfate tablet or methadone tablet in water is often as effective as more complex solutions like Brompton's

  - The pain of many terminal patients can be adequately controlled on an oral morphine regimen of 20 mg or less every 3 hours

  - Many institutions have their own mixtures of Brompton's cocktail or other analgesic drug cocktails

  - Recent controlled studies have shown that neither Bromptom's cocktail nor heroin has any advantage over morphine as analgesics (Twycross, 1977)

2. Intramuscular

- Consider routes other than IM: painful to administer; may cause muscle and/or nerve damage; poor absorption in patients with poor muscle mass; difficult for patients to self-administer; duration of analgesic effect shorter than with oral administration

3. Intravenous

- IV push analgesia lasts only 1-2 hours. Use continuous drip not IV push

- Continuous drip gives constant level of analgesia

- Example of IV dose: Morphine Sulfate 18 mg in 100 cc Normal saline to run over 6 hours

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

d. Duration of action

- Greatest difference of narcotics is in duration of action

- A common reason for inadequate pain control is administration of analgesics at intervals which exceed the duration of action of the analgesic

- Know the duration of action for each analgesic administered

  - Demerol IM has duration less than 3 hours

  - Levodromoran and methadone have greatest duration of action (6-12 hours)

e. Side effects of narcotic administration

- Tolerance

  - A characteristic which requires increasing larger doses of a drug to provide the same effect as was produced by the original dose

  - First sign of tolerance is a decrease in the duration of the drug's effect, next comes a decrease in the analgesic effect

  - Tolerance develops irregularly. Some patients may need larger doses every few weeks; others may never need to increase the dose; still others need to decrease the dose periodically

  - Many people fear that there will be no dose to relieve the end-stage pain; according to research done by McCaffrey (1979) there is no data to suggest a ceiling on the analgesic effects of narcotics, i.e., the patient can always take more. Original studies showed tolerance by 10 days. But study done on drug addicts, now know many patients never reach tolerance-may plateau

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

  - Patient develops tolerance to respiratory depression at the same time he becomes tolerant to analgesic effects (Mc Caffrey, 1979)

- Sedation
  - Often the first 2-3 days of effective pain relief the patient appears sedated and sleeps for hours; chronic pain is exhausting
  - Usually a narrow dosage range between pain relief and sedation
  - Do not equate sedation with pain relief
  - Sedation may also be due to drugs other than narcotics, psychological factors, physical ability, or other pathology
  - Instruct patient and family that sedation may occur but usually subsides in a few days; persistent or increasing sedation warrants assessment
  - May add caffeine beverages or amphetamine to counteract sedation but be aware of other problems that may occur

- Respiratory Depression
  - Usually preceded by sedation
  - Precautions should be taken if respirations are 10 or below or if the cause of pain is suddenly removed
  - Always have a baseline respiratory rate for each patient
  - Pain appears to be nature's physiological antedote to the respiratory depressant effects of narcotics (McCaffrey, 1979)

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- It has been shown that tolerance to respiratory depression develops at the same rate as tolerance to analgesia (Houde, 1974)
- Treatment for narcotic-induced respiratory depression includes instructing patient to breathe, artificial or mouth-mouth ventilation, IV Narcan, and careful observation of patient's status
  - -- May need to repeat Narcan several times since duration of action of Narcan is 1-2 hours

- Nausea and Vomiting
  - Sometimes mistaken for allergic reactions and patients may be denied narcotics
  - Consider rectal suppositories for analgesia instead of oral if patient is nauseated. E.g., Numorphan 10 mg rectally equals morphine sulfate 10 mg IM
  - Treat nausea
    - -- phenothiazenes (Compazine® act on the medullary source of nausea)
    - -- antihistamines (Dramamine® attack the second source of nausea, vestibular)

- Constipation
  - Prevent constipation by giving stool softeners before this problem occurs
  - Include ample intake of fluids, exercise, foods high in bulk and roughage
  - Use of TENS to the abdomen will also help increase peristalsis

13. Use of other medications to control pain

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

a. "Potentiators"

- By definition should add to the analgesic effect of narcotics
- There are few true potentiators; most are additives, i.e., a drug that adds an effect to the action of another drug
- Phenergan is often used with narcotics and is actually an anti-analgesic, e.g., Demerol 50 mg IM with Phenergan 25 mg = Demerol 25 mg IM
  - Vistaril is the drug of choice because it does potentiate the analgesic effect

b. Tricyclics

- Many patients with chronic pain are depressed as a distinct additional problem or due to the realization of their disease or the effects of chronic pain
- Treating underlying depression with tricyclic anti-depressant may help in pain relief
  - Some patients who are depressed have decreased serotonin levels. With decreased serotonin the transmission of pain occurs more rapidly (normally serotonin helps block pain transmission). By increasing the production of serotonin (giving anti-depressants) there may be additional pain relief by helping to block some of the patient's pain
  - Tricyclics usually produce sedation at bedtime when given the total daily dose 2-3 hours before bedtime
  - Analgesia is usually produced within 10 days and anti-depressant effects within 14-21 days (McCaffrey, 1979)

14. Placebos

- Measure how much trust or confidence the patient has in nurse
    - It is estimated that one-third of the entire patient population will respond positively to a placebo at some time
    - Very often the patient discovers that a placebo has been given and this destroys all trust
    - Placebos usually help patients by reducing their anxiety because they trust that they have been given something to help them
    - If patients respond to a placebo it means that they have some ability to control their own pain process so that other measures besides medications may help them relieve their pain.

NOTE TO INSTRUCTOR

The following questions should be discussed by the group following above item.

Discussion Questions

1. What have been your past experiences in dealing with patients who receive placebos?
2. How do you feel when you administer a placebo?

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

## GUIDELINES FOR USING PAIN RELIEF MEASURES

Margo McCaffery

1. Use a variety of pain relief measures.
2. Use pain relief measures before pain becomes severe.
3. Include those pain relief measures that the patient believes will be effective.
4. Take into account the patient's ability or willingness to be active or passive in the application of the pain relief measure.
5. Regarding the potency of the pain relief measure needed, rely upon the patient's behavior indicating the severity of the pain rather than relying on the known physical stimuli.
6. If the pain relief measure is ineffective the first time it is used, especially if the patient never tried it before, encourage the patient to try it at least one or two more times before abandoning it.
7. Be open minded about what may relieve pain.
8. Keep trying. Do not let failure cause you to abandon the patient.
    a. The only failure is in abandoning the patient.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

IX. Non-Nursing Interventions

A. Acupuncture

1. There are approximately 1,000 known acupuncture points, forming 14 basic groups known as meridians. Each meridian is associated with a particular organ. Meridians are a series of longitudinal lines which terminate at the fingers or toes

    a. A diseased organ may generate a pain or sensation along its meridian

2. Mechanism of action: Stimulates large fibers or overloads central biasing mechanism

3. Needles of varying lengths are inserted in a downward, rotating motion at the appropriate acupuncture points for the purpose of both healing and relieving pain (Armstrong, 1972). Electrical stimulation via needles has also been used

B. Chordotomy

1. Principles behind chordotomies

    a. Pain fibers cross in the spinal cord (anterolateral tract)

    b. Cutting the anterolateral (or spinothalmic) tract will produce analgesia without loss of sensation

    c. The level at which the lesion must be created depends on the location of the pain

    d. Surgery must be performed at least 5-6 segments above the highest level of pain

    e. For pain in the lower 1/2 of the body, high thoracic tractotomy is indicated

f. For pain in thorax, upper extremities or shoulders, high cervical or medullary tractotomy is indicated

2. Types of Chordotomy

a. Unilateral - less risk of complications

b. Bilateral

- Can be performed in one stage at the thoracic level
- Two separate procedures for higher levels due to risk of respiratory failure in one stage procedures at high levels

c. Surgical or open

- Laminectomy to expose cord for incision
- Becoming outmoded

d. Percutaneous

- Transcutaneous insertion into spinal cord of a needle through which an electrode passes to coagulate and destroy spinothalmic fibers
- Advantage of no general anesthesia or open procedure
- About 45 minutes long and varies from five minutes to one hour
- Post-op care: analgesics for headache or pain; catheterize if urine retention; support patient on each side when standing on the following day

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | 3. Possible Side Effects<br>a. May be transient; pain recurs in time<br>b. Hemiparesis<br>c. Ataxia<br>d. Sleep apnea with bilateral cordotomy<br>e. Bladder retention or incontinence (usually transient in unilateral) tends to recover in time with bilateral<br>f. Sexual function in males is lost following bilateral<br>4. Patient Teaching<br>a. Warn patient about taking precautions after procedure due to loss of pain and temperature sensation |

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

## SECTION C: NUTRITIONAL IMPAIRMENTS AND RELATED PROBLEMS

I. Rationale for emphasis on nutrition

A. Based on the clinical and observable effects of cancer on the individual and the vulnerability of his/her nutritional status, it is considered appropriate that great effort be made to improve or maintain the quality of of life which contributes to a reasonable comfortable and functioning person. It cannot be assumed that because a person has a malignant disease, that malnutrition and/or physical wasting are a normal part of the symptomatology. While the relationship cannot be denied in caring for the person, these should be treated as two separate components of the plan of care. Valid goal because food is an important value in our society.

1. Adequate nutrition is a valid goal even when therapeutic measures have been withdrawn and can provide:

    a. Vital role in improving morale

    b. Increased tolerance for palliative interventions

    c. Longer hospital free period

    d. Improved quality of life

B. Frequent symptoms of anorexia, nausea, vomiting and wasting of body tissues seen in persons with malignant disease have been attributed to a variety of causes and effects relating to: (Shils, 1980)

1. Malignant tumor activity in the body such as:

    a. Changes in metabolic rate

    b. Altered taste preceptions

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | c. Energy expenditure vs. energy requirements<br>d. Competition of the tumor vs. host for nutrients<br>2. Nutritional disorders related to treatment modalities:<br>a. Radiation Therapy--side-effects of nausea, vomiting, anorexia, loss of taste, decreased salivation, mucositis, dental caries, intestinal obstruction or malabsorption<br>b. Surgical Treatment--malabsorption after resection of parts of the GI tract, dependence on tube feedings after resection of oropharyngeal area, difficulty chewing or swallowing after head and neck surgery, dumping syndrome after a gastrectomy, or diarrhea, water and electrolyte imbalance after colostomy or ileostomy surgery<br>c. Chemotherapy--side-effects of nausea, vomiting, anorexia, diarrhea, stomatitis and malabsorption commonly seen with chemotherapeutic drugs used |

## CANCER THERAPEUTIC AGENTS THAT CAN ADVERSELY AFFECT DESIRE FOR FOOD

| DRUGS | EFFECTS | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Anorexia | Nausea | Vomiting | Stomatitis | Diarrhea | Constipation | Metalic Taste | Hepatic Dysfunction | Abdominal Pain |
| Actinomycin-D | | X | X | X | X | | | | |
| Adriamycin | | X | X | X | X | | | | |
| BCNU | | X | X | | | | | X | |
| Bleomycin | X | X | X | X | | | | | |
| CCNU | | X | X | | | | | | |
| Chlorambucil (Leukeran) | X | X | X | | | | | | |
| Cis-Platinum | | X | X | | | | | | |
| Cytosine Arabinoside (Ara-C) | X | X | X | X | | | | X | |
| Cytoxan | X | X | X | X | | | | | |
| Daunorubicin | | X | X | X | | | | | |
| Dacarbazine - (DTIC, DIC) | | X | X | | X | | | | |
| 5-Fluorouracil | X | X | X | X | X | | | | |
| Hydroxyurea | X | X | X | X | | | | | |
| L-Asparaginase | X | X | X | | | | | X | |
| Melphalan (Alkeran) | X | X | X | | | | | | |
| 6-Mercaptopurine | X | X | X | X | X | | | X | |

| DRUGS | EFFECTS | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Anorexia | Nausea | Vomiting | Stomatitis | Diarrhea | Constipation | Metalic Taste | Hepatic Disfunction | Abdominal Pain |
| Methotrexate | | | | X | X | | | X | |
| Methyl-CCNU | | X | X | | | | | | |
| Mithromycin | | X | X | | | | | X | |
| Nitrogen Mustard | X | X | X | | | | X | | |
| Procarbazine | | X | X | X | X | | | | |
| Vinblastine (Velban) | | X | X | X | X | X | | | X |
| Vincristine (Oncovin) | | X | X | | | | | | X |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

II. Anorexia - Most common symptom

- A. Definition - decline of food intake below metabolic need
- B. Causes of Anorexia
  - 1. Theories - neural, physical and chemical signals stimulate peripheral and central receptors to regulate food intake. Alteration in only one area probably will not have a significant result.
  - 2. Central Hypothalamic Controls (DeWys, 1977)
    - a. Alpha adrenergic receptors located in medial hypothalamus stimulate feeding behavior
    - b. Beta adrenergic and dopamine receptors located in anterolateral hypothalamus suppress feeding behavior
    - c. Significance in cancer patient:
      - ● Stress (of illness) may release beta adrenergic and dopaminergic substances leading to suppressed appetite
  - 3. Visceral Sensitive Effects
    - a. Receptors in oral cavity and viscera are sensitive to the osmotic volumetric and chemical properties of ingested material
    - b. Oral receptors trigger physiological responses of swallowing, flow of saliva, gastric contractions, gastric and intestinal secretions
    - c. Gate receptors sense amount of glucose and amino acids present. Both neural and humoral influence inhibit further intake

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

d. Significance in cancer patient:

- Decreased oral stimuli (decreased taste, stomatitis, dry mouth, radiation effects) with decreased physiologic responses necessary for digestion causes prolonged process with inhibition of further intake

- Atrophic changes in the mucosa of small intestine (due to malnutrition, radiation effects) delay assimilation of nutrients

4. Glucosensitive Effects

a. Glucoreceptor cells are present in the hypothalamus and the liver when stimulated to certain levels fire a satiety signal

b. Significance in cancer patient:

- Associated neoplasin is a five to six fold increase in glucose transport into the tumor. This glucose is metabolized via anaerobic glycolysis. Anaerobic glycolysis involves the conversion of glucose to lactate in the liver (known as the Cori cycle), and return of this to the tumor for use as energy

- The conversion of glucose to (lactate) before being used for energy is inefficient in that it yields only 2 percent of the total energy of a glucose molecule (Brennan, 1977)

- Possible that the continuous recycling of glucose (Cori cycle) effects a satiety signal

- In addition, this anaerobic glycolysis acts as an energy drain on the host, raising intake requirements to meet basal metabolic needs

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

5. Liposensitive Effects

Food intake is also influenced by body lipids with sensors for free fatty acids and glycerol. (DeWys 1979). Fat is stored in adipose cells in the form of triglycerides composed of fatty acids attached to a glycerol backbone. (Schein, 1979). Lipolysis is the release of free fatty acids into the blood and glycerol for gluconeogenesis in the liver. In patients with cancer fasting free fatty acids may be normal, but there may be a disturbance in the free fatty acid-triglyceride axis in that there is a greater return of free fatty acid from triglyceride and high carbohydrate feeding does not block the lipolysis. (DeWys, 1979). Thus the glucoreceptors in the liver register a high rate of glucose utilization and may effect a satiety signal in the ventromedial hypothalamus.

6. Taste Disturbances

a. A positive taste stimulus triggers multiple physiologic reflexes that are conducive to food intake

b. Patients with increased taste thresholds may not receive a positive taste stimulus strong enough to trigger these physiologic reflexes

- Cycle fails to provide adequate oral secretions which leads to dysphagia
- Inadequate secretion of gastric secretions leads to patients experiencing a sense of early fullness
- Inadequate pancreatic secretion leads to sluggish digestion of the first meal of the day which leads to decreased eating of meals later in the day

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

III. Nausea and Vomiting: Next to pain is most common problem reported and we have difficulty managing these symptoms.

   A. One of the most common complaints, these are caused by the disease itself or by the treatments being used to combat the neoplasm

   B. Physiology

      1. Nausea - conscious recognition of excitation of a part of the brain associated with control of vomiting. Common causes include irritation of the duodenum or small intestine, certain emetic substances

      2. Vomiting - stimulation of the vomiting control center in the medulla institutes muscle reactions that forcefully rid the upper gastrointestinal tract of contents

   C. Causative factors in cancer patients

      1. Radiation Therapy

         a. The epithelium of the small intestine is second only to bone marrow in its sensitivity to radiation

         b. GI irradiation therapy can cause diarrhea, malabsorption of nutrients, obstruction in the intestinal system, anorexia and irritation sufficient to produce nausea/vomiting

         c. Head and neck region irradiation can result in destruction or alteration of the sense of taste, decreased salivation, mucositis and dental problems directly or indirectly leading to the sensation of nausea or vomiting

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | 2. Chemotherapy<br>a. These drugs can adversly affect the function of the gastrointestinal tract (Shils, 1980, p. 1185)<br>b. Direct effect on vomiting center possible |

# ANTIEMETIC AGENTS USED IN THE CONTROL OF NAUSEA AND VOMITING

| DRUG | ROUTE | DOSAGE | DURATION OF ACTION |
|---|---|---|---|
| Bonine | PO | 25-50mg [illegible]/day | 8-24 hours |
| Compazine | PO | 5-10mg 3-4x/day | 3-4 hours |
| | R | 25mg 2x/day | 3-4 hours |
| | IM | 5-10mg 3-4x/day | 3-4 hours |
| | IV | 20mg/liter | 3-4 hours |
| Dramamine | PO | 50-100mg q4hr | 4-6 hours |
| | IM | 50mg q4hr | 4-6 hours |
| | R | 100mg 1-2x/day | 4-6 hours |
| Emete-Con | IM | 50mg q3-4 hrs. | 3-4 hours |
| | IV | 25mg q4 hrs. | 3-4 hours |
| Marezine | PO | 50mg 14-6 hrs. | 4-6 hours |
| | R | 100mg q 4-6 hours | 4-6 hours |
| | IM | 50mg q 4-6 hours | 4-6 hours |
| Phenergan | PO,R | *12.5-50mg q4-6 hrs. | 4-6 hours |
| | IM,IV | *12.5-50mg q4-6 hrs.<br>(*Highly individualized dosage) | 4-6 hours |
| Tigan | PO | 25mg q3-4 hrs. | 3-4 hours |
| | R | 200mg q3-4 hrs. | 3-4 hours |
| | IM | 200mg q3-4 hrs. | 2-3 hours |
| Torecan | PO | 10mg 1-3x/day | 3-4 hours |
| | R | 10mg 1-3x/day | 3-4 hours |
| | IM | 10mg 1-3x/day | 3-4 hours |
| Vistaril | PO | 25-100mg 3-4x/day | 4-6 hours |
| | IM | 25-100mg 4-6 hrs. | 4-6 hours |
| Vontrol | PO,R | 25-50mg q4h | 3-6 hours |
| | IM | 20-40mg q4h | 3-6 hours |
| | IV | 20mg 1-2x/day | 4-6 hours |
| | | | |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

3. Sensory Input - altered taste and smell sensations
    a. Sensations can either initiate salivation, gastric secretions and motor responses to hunger or they can inhibit these responses, thus supressing appetite and provoking feelings of nausea and possible vomiting
    b. Odors may stimulate vomiting
4. Emotional Factors
    a. Depression, anxiety, pain and fear play an important role in the sensations of anorexia, nausea and vomiting experienced by the person with cancer
    b. Affect the ability to eat as well as the retention of the food ingested

IV. Disorders of Taste in Cancer

Assess sense of smell as well as taste.

A. Definitions
1. Ageusia - Absence of taste. Unable to taste or differentiate, sweet, salt, sour and/or bitter
2. Hypogeusia - Decrease in taste sensation
3. Cacogeusia - Sensation whereby everything tastes bad. Often is a repelling taste. Is especially associated with ingestion of eggs, meat, poultry, fish, garlic, onions, tomatoes, coffee, chocolate and fried foods.
4. Dysgeusia - Difficulty in taste perception.
5. Decreased taste threshold - A diminished small amount of a substance is needed to stimulate the taste perception

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

6. Elevated taste threshold - An increased amount of a substance (or concentration) is needed to stimulate the taste perception

7. Tastant - a substance or material which is sweet, sour, bitter and/or acid

B. Anatomy and physiology involved with the taste process

1. Taste is associated with the taste buds Nervous innervation to taste buds lies in lingual structures called papillae

   a. Fungiform papillae - lie on anterior lingual surface. Are small, sometimes raised, and often pigmented. 0-8 taste buds lie in this area

   b. Circumvallate papillae - lie on posterior one-third of tongue. Are larger, taller papillae. Approximately 100 taste buds lie in this area

2. Including the tongue, the palate, pharnyx and laryngeal areas have papillae that contain taste receptors. Patient with dentures have lowered taste perception.

   a. Salt and sweet are perceived more acutely on tongue than bitter and sour

   b. Sour and bitter are perceived more acutely on palate than salt and sweet

   c. All four tastes are perceived but to a lesser degree in the laryngeal area

C. There are many theories about the causes of taste abnormalities in cancer patients: due either to the disease process and/or modes of treatment

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

1. Deficiency state occuring as a result of malignancy, in particular a zinc deficiency, has been related to a decrease in taste acuity
    a. Causes an elevation of taste thresholds
    b. Taste abnormalities that are a result of this deficiency state can be corrected with daily administration of zinc sulfate 15mg every day. Zinc sulfate may cause gastric upset
2. Chemotherapy
    a. Local mucosal irritation stimulates some taste bud cells
    b. Occurs most frequently with drugs in the antimetabolite and antibiotic groups
3. Radiation therapy
    a. Destructive effect of radiation on taste buds may cause taste distortions
    b. Xerostomia (absence of saliva) that occurs as a result of radiation to the salivary glands may cause taste abnormalities

D. Patient's subjective symptoms - Many variations in description of taste changes

1. Most commonly:
    a. Elevated threshold for sweets (need more sweet - #1 problem)
    b. Decreased threshold for bitter taste (taste bitter easily - #2 problem)

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

2. Persistent sensation of saltiness, sweetness, sourness, or bitterness - i.e., all foods taste the same

3. Constant metallic taste in the absence of food

   a. Salt may have an intensely metallic taste

4. Taste and odor of foods may be described as "rotten", "manure-like", or like decaying garbage

   Specific foods causing these symptoms are the following

   a. Meats, eggs, fish, sharp cheeses

   b. Bread, coffee, tomatoes

   c. Onions, garlic and other spices

5. Eating may be described as chewing or swallowing flour paste or sawdust

V. Stomatitis

   A. Definition

      1. Refers to the inflammatory reaction and ulcerative lesions of the mouth and oropharynx

         a. Painful, ulcerative lesions (some people have severe ulcerations without pain)

         b. Appear as white patches or inflammed mucosa

         c. Appear on buccal mucosa, hard and soft palates, uvula, tongue, lip, posterior pharyngeal wall

      2. Usually develops 7-14 days after receiving certain chemotherapeutic agents

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | a. Antimetabolites - 5 FU, methotrexate, Cytosar<br>b. Antibiotics: dactinomycin<br>c. Vinca alkaloids: vinblastine (Velban)<br>3. Develops approximately two weeks after initiation of radiation therapy to the head and neck area<br>4. Develops from infection secondary to poor oral hygiene/dehydration<br>B. Detection and recognition of stomatitis<br>1. Normal healthy mouth<br>a. Adequacy of mechanisms for maintaining oral hygiene<br>● Adequate flow of salivia<br>● Consistency normally thin and "water-like"<br>● pH normally 7.5<br>● Normal muscular movements of mouth (remove food and debris from the area)<br>● Movement of food (act as a detergent to cleanse the mouth)<br>b. Tongue<br>● Normally pink and moist<br>● Visible but not prominent papillae<br>c. Lips - normally pink and moist<br>2. Oral examination including changes to look for as stomatitis worsens. (See Exhibit) |

# ORAL EXAM GUIDE

| | NUMERICAL AND DESCRIPTIVE RATINGS | | | |
|---|---|---|---|---|
| CATEGORY | 1 | 2 | 3 | 4 |
| LIPS | | | | |
| Texture | • smooth, soft | • slightly wrinkled | • rough | • cracked, bleeding or ulcerated |
| Color | • pink | • one ore more reddened areas | • inflammatory line of demarcation | • entire lip inflamed, bleeding |
| Moisture | • moist | • slightly dry | • swollen and dry may be blistered | • cracked and very dry |
| TONGUE | | | | |
| Texture | • firm without fissures or prominent papilli | • papilli prominent particularly at base medical lingual groove deepened | • papilli all over tongue raised giving a peppered appearance; coating at the base | • coating extended with a line of demarcation at the tip; or engorged, deeply grooved and thicker than normal |
| Color | • pink | • pink with reddened areas or coated without reddened areas | • entire tongue red but tip and papilli are redder | • tip is very red and is demarcated with the coating; sides are blistered |
| Moisture | • moist | • slightly dry | • very dry and swollen | • intensely dry with indentations |
| MUCOUS MEMBRANES OF THE PALATE, UVULA AND TONSILLAR FOSSA | | | | |
| Color | • pink | • pale | • red and inflamed; may have white coating | • very red; may have pinpoint brown spots or ulcerations |
| Moisture | • moist | • slightly dry | • dry and swollen | • blistered and/or ulcerated |
| GINGIVA | | | | |
| Color | • pink | • pale; may have one or more reddened areas or white pustules | • red with ulcerations | • very red and shiny |
| Moisture | • moist | • slightly dry | • dry and edematous | • edematous with ulcerations and bleeding |
| TEETH | | | | |
| Shine | • shiny | • slightly dull | • dull | • very dull |
| Debris | • no debris | • slight debris | • debris clinging to ¼ of visible enamel | • covered with debris |
| Dentures | • well-fitting | • slightly loose | • loose and ill-fitting with areas of irritation | • unable to wear due to irritation |
| SALIVA | • thin, watery | • increase in amount | • saliva scanty; mouth dry | • saliva thick and ropy, viscid or mucid |
| VOICE | • normal tone and quality | • slight change; voice is lower | • deep and raspy | • difficulty talking noticeable, particularly articulation |
| ABILITY TO SWALLOW | • normal gag reflex; swallows without difficulty | • discomfort on swallowing | • diminished gag reflex and/or pain on swallowing | • no gag relfex and/or inability to swallow |

*Reprint with permission: Masson Publishing USA, Inc. - Beck, S. "Impact of a Systematic Oral Care Protocol on Stomatitis after Chemotherapy," Cancer Nursing, 1979, 2, p. 192.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

a. Examine oral cavity before any treatment modality is instituted to obtain baseline date from which to make comparisons

- Daily inspection of oral cavity is necessary
- Always use flashlight and tongue blade when inspecting
- For consistency and accuracy of reporting results, if possible the same person should routinely do the oral examinations

b. Inspect lips, tongue, floor of mouth, buccal mucosa, hard and soft palate, uvula, posterior pharyngeal wall using flashlight and tongue blade

c. Inspect color, texture, moisture and presence or absence or debri

d. Changes to note in saliva

- Initially increased salivation occurs as body attempts to respond to the call for more fluid
- Later stages, saliva becomes very thick and ropey

e. Mucosal changes

- Paling and drying of mucosa as temperature changes in oral cavity occur due to increased mouth breathing
- Paling due to vasoconstriction occurs in an attempt to conserve body heat and fluid (response to stress)

f. Changes in the tongue

- Tongue shrinks forcing papillae to become noticeably prominent

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | • Coating on surface of tongue to cover mucous membrane occurs by a chemical adaptation in response to continual dehydration and mouth breathing<br>• Taste buds on tongue become plugged with thick mucoid saliva resulting in decreased taste sensation<br>g. Changes in the lips<br>• Line of demarcation forms between outer, more dehydrated portion of lip from the inner, more hydrated aspect of the lip<br>• Next, the mucosa becomes generally inflamed and breaks<br>3. Summary<br>a. Signs and symptoms of mild stomatitis<br>• Will exhibit mild erythema<br>• Complains of mouth dryness<br>• Patient may complain of slight burning sensation<br>b. Signs and symptoms of severe stomatitis<br>• Exhibits ulceration<br>• Glossal edema evidenced<br>• Infection in oral cavity occurs<br>4. Mouth care<br>a. Debate over what to use<br>b. Never use lemon<br>c. Saline mouth irrigations seem best |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

IV. Nutritional Assessment

- A. Should be obtained early in contact with patient before nutritional problems develop - obtain baseline data.
- B. Establish rapport with patient so that she/he will be amenable to suggestions when problems do develop
- C. Should identify and/or anticipate nutritional problems based on history, disease, effects of disease and/or treatment
- D. Diet history (See Nutritional - Assessment Form)
  - 1. Appetite
    - a. Recent changes in amount of intake and food preferences
    - b. Alterations in taste/smell perceptions
    - c. Important to address your questions specifically to the issue of taste vs. appetite to differentiate between the two
    - d. Determine specific foods involved in the experience of a change in taste
  - 2. Diet pattern
    - a. The types and quantity of food ingested
    - b. Patient's understanding of nutrition, i.e., does she/he know what protein, CHO and fat are, and what foods contain them
    - c. Intolerance to certain foods; what results and how they are managed
    - d. Favorite foods - save for special days so patients don't end up disliking their favorite foods

# NUTRITIONAL ASSESSMENT FORM

## GENERAL INFORMATION

Name ______________________________

Address ______________________________

Telephone Number ____________ Age _____ Sex _____ Marital Status __________

Ethnic and/or Religious Background as related to diet: ______________

______________________________

Primary Diagnosis ______________ Physician ______________

Present Problem ______________________________

Recent Illness, Surgery or Treatment ______________

## DIETARY HISTORY

Diet ______________ Allergies ______________

Food Preferences ______________________________

Food Dislikes ______________________________

Appetite ______________ Any appetite changes? __________

If appetite changes, please describe ______________

Dentures: Upper ____ Lower ____ Chewing: Normal ________ Impaired ________

Swallowing: Normal ____________ Impaired ____________

Usual Meal Times: (A.M.) ________ (Noon/Aft.) _______ (Evening) __________

Snacks: Yes ______ No ______ Times ______________

Occupation: ______________ Physical Activity (Type, amount and frequency) ______________________________

Assessment of Activity (Please circle): sedentary moderately active very active

Medications ________________________________________________

Urinary Habits ______________________________________________

Bowel Habits ________________________________________________

## PHYSICAL EXAMINATION

Assessment of general physical condition ______________________

____________________________________________________________

Height __________ Weight: Today's Date __________________ Weight ___________

Date of Onset of Illness __________________ Weight ___________

Length of Illness _____________ Weight ___________

Anthropometric Measurements:

- Mid-upper Arm Circumference: R/L _____________ cm __________% of Standard
- Muscle Circumference: R/L _____________ cm __________% of Standard
- Triceps Skin-fold: R/L _____________ cm __________% of Standard

## LABORATORY VALUES

Blood: Hemaglobin _____________

Hematocrit _____________

Serum Albumin __________

Transferrin _____________

Total Lymphocyte Count __________

Urine: Protein ____________

Glucose ____________

Acetone ____________

Modified from Keithley, J. "Proper Nutritional Assessment Can Prevent Hospital Malnutrition," Nursing 79, 2, 1979, 68-72.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | e. What are the attitudes and beliefs regarding foods<br>3. Eating patterns<br>a. When, where and with whom does patient eat<br>b. Who prepared food - whoever prepares should be part of planning<br>c. Appetite increased or decreased if contact with food (as in preparation of meals)<br>4. Chewing and swallowing<br>a. Ability to masticate<br>b. Use of dentures<br>c. Pain in mouth or on swallowing<br>d. Decreased salivation<br>5. Physical activity<br>a. Describe typical days activity. How much, or is patient bedridden. (A decreased appetite lends itself to lassitude, apathy, which further decreases intake)<br>6. Medication history<br>a. Any medication that affects appetite, assimilation of nutrients or activity level. Do they affect patient's ability to stay awake and eat<br>7. Illness/Surgeries/Radiation Therapy<br>a. Specifically chronic gastrointestinal diseases<br>b. Surgery involving alimentary tract |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

c. Field and dose of radiation

8. Sociocultural and religious factors

   a. Modification in food preparation, selection and pattern of intake that are important to his/her ethnic background and religious practices

9. Elimination practices

   a. Usual pattern

   b. Recent changes

   c. Use of laxatives, antidiarrheals

10. Contributing symptomatology

    a. Pain, neuromuscular problems, sensory deficits, fatigue, depression - assess how these interfere with eating

E. Physical examination

1. Weight

   a. Record normal weight, present weight and temporal quality of change

   b. Realistic goal is maintenance of present weight rather than return to normal weight; impress on patient that even this is a worthy accomplishment

2. Anthropometric measurements provide a simple means to evaluate degree of muscle depletion or loss of caloric reserves

   a. Mid-arm circumference and Muscle circumference - an assessment of skeletal muscle compartments or lean body mass

      - "fuel stores," the malnourished body utilizes both fat and protein for energy

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- Broken down to supply smino acids for making new proteins

b. Triceps skin-fold - a measurement of the subcutaneous fat reserves (energy available)

c. Laboratory values which indicate nutritional status - (1, 2 and 3 are commonly available. Since non-invasive methods of assessment are available, laboratory testing is not considered a necessary addition except during or prior to active treatment periods)

- Hemaglobin - an indicator of iron deficiency or anemia
  - Severly malnourished men = <12; women - <10
- Hematocrit - an indicator of the erythrocytes that are present
  - Severly malnourished - men = <37; women = <31
- Serum albumin - carrier or transport
  - Protein carried in the blood
  - Produced in the liver
  - Reserves have to be used up before malnutrition is reflected in serum albumin levels which can take as long as two weeks
  - Protein depletion - 150 mg%
- Serum transferrin - a circulating protein produced in the liver which transports iron in the body
  - A good short-term indicator of visceral depletion or protein malnutrition

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- Protein depletion - 150mg%

- Total iron binding capacity - an indirect measure of serum transferrin
  - Depressed transferrin suspected whenever the TIBC is less than 250ug per 100mls

- Urine - indicate whether the person is excreting blood, albumin, glucose, bilirubin or acetone in his/her urine
  - Urine tests for nitrogen and creatinine can be used for assessing nutritional status
  - Decreased urea clearance may reflect an active tubular reabsorption or urea in the face of nitrogen deficiency
  - Low creatinine levels result from decreased muscle mass from which creatinine is derived

VII. Strategies for modifying food intake

A. Minimize other negative symptoms

- Impress on patient and staff that eating is a treatment and that it increases the quality of life
- Involve families in planning for interventions
- Be realistic and listen to what patient wants to do

1. Pain - assure adequate relief especially at and following meal time

2. Emotional Dysphoria. Results of a Beck Depression inventory implied that cancer patients' emotions are related to their

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physical symptoms of decreased appetite and weight loss

Nutrition management is an area in which a cancer patient could and should have a participatory role and this may decrease dysphoria

3. Fatigue is a subjective evaluation of sensations associated with discomfort, decrease in motor and mental skill and increased task aversion

4. Causes of fatigue include physiological factors as follows:

   a. Malnutrition

      - Negative nitrogen balance resulting from decreased protein intake
      - Ketosis resulting from decreased caloric intake and using fat stores in body for energy

   b. Poor cardiopulmonary reserve

      - Metastasis
      - Effects of therapy on lungs
      - Age
      - Chronic illness
      - Terminal processes

   c. Prolonged mental and/or physical stress

   d. Side effects of drugs: sedatives, hypnotics, tranquilizers, antihistamines, analgesics, tetracycline, adrenocorticosteroids, ergot, insulin, digitalis

      - Interfere with REM sleep

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| | e. Effects of therapy<br>• Anemia from chemotherapy<br>• Accumulation of byproducts of cellular destruction from radiation<br>• Extra energy required to maintain cell growth in cancer cells<br>• Extra energy required for healing after surgery<br>f. Anemia<br>g. Infection<br>• Extra energy required with fever<br>• Byproducts of cell destruction accumulate causing fatigue<br>h. Electrolyte disturbances<br>• ↓Na, ↑ or ↓Mg, ↓K<br>i. Renal or hepatic dysfunction<br>j. Endocrine disorders<br>• Diabetes, alterations in pituitary, adrenal, thyroid or parathyroid function |

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B. Motivate patient

1. Impress on patient that nutrition is part of treatment (control or palliative)

2. People associate illness with decreased appetite. Need to interrupt cycle of anorexia--malnutrition--atrophy of GI mucosa--assimilation--inhibition of intake--malnutrition

3. Compliance increases with knowledge of nutritional disturbance

4. Provide for patients and/or families active participation in nutritional treatment program. Suggestions: (1) daily food diary and recording of timing of negative symptoms; (2) taste testing nutritional supplements; (3) meal and recipe planning. Caution: are your expectations/plans realistic as far as patient/family capabilities/resources?

5. Begin with a realistic, short term goal. The goal should be:

   a. Agreed to by the patient/family

   b. Measurable in a way the patient can understand (i.e., weight gain, calorie increase, volume increase)

   c. Given as feedback and positive reinforcement

6. Capitalize on environmental asthetics to create an ambient atmosphere at meal times

   a. Patient cleanliness

   b. Environmental cleanliness: removal of soiled linen, dressing, malodorous objects

   c. Make meal time a special event

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| | d. Get patient out of bed to eat (if not too exhausting)<br>e. Provide for social interaction at meal time<br>7. Provide the necessary assistance patient needs to eat (learned in diet history)<br>8. Allow patient choice of his own foods as close to meal time as possible. Encourage variety to avoid taste fatigue<br>9. Arrange for small, frequent meals; nutritious snacks should be available at all times<br>10. Achieving modification will depend upon closely matching patients' life style with regime<br>11. A moderate amount of exercise is necessary to promote anabolism. For a patient who cannot ambulate, simple bed exercises can be done - i.e., quadricep setting, pushing against a foot board, chin ups using a trapeze, isometrics<br>C. Improve nutrient intake: all suggestions must be evaluated for appropriateness, practicality and acceptability for a given patient<br>1. Instruct patient/family<br>a. Instruct on basic nutrition<br>● Meet the needs of your patient learned in the history<br>● Useful patient teaching tools listed on reference list<br>b. Involve patient and family in the goal and nutritional care plan<br>● Share rationale for all interventions |

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| | c. Actively discourage family from force feeding patient. Suggest alternate activities for family members<br>● Suggest they eat with the patient, family style<br>● Preparation of small nutritious snack foods, meals brought from home or prepared by family in unit for patient between meals/instead of meals/during night<br>● Suggest decorating the room, bringing reminders of home to the hospital; this may improve morale which affects appetite<br>● Compliment their efforts<br>● Wine or stout shared at meals may increase appetite<br>d. Modify their pattern to a regimen of snacking, finger foods and a breakfast high in protein and calories<br>2. Avoid empty calories (even substitute juices, supplements, high protein drinks, etc., for water)<br>3. Add calories and protein in diet that add the least amount of volume to the diet<br>4. Ways to power-pack general diet (see Handout) |

## POWER PACKING NORMAL FOODS

A. In recipes using milk or for drinking mile alone all 1 cup nonfat dry mil powder to a quart of whole milk. This is called fortified milk.

880 calories, 56 gm protein per quart
220 calories, 14 gm protein per cup

Cream can also be substituted for milk when called for in recipes. Skim milk will restrict fat content if required without reducing protein. For lactose intolerant patients Mocha Mix• or Dairy Rich• can be used in place of milk. (Rosenbaum, p. 4-57)

B. Suggestions for adding calories without increasing volume:

- Melt butter generously on soups, vegetables, toast, hot cereals, rice, soft cooked eggs. 1 tsp. butter adds 35 calories.

- Add sour cream to meats, fruits, baked potatoes. 1 Tbls. sour cream adds 72 calories.

- Substitute mayonnaise for salad dressing. 1 Tbls. mayonnaise has 100 calories.

- Top pies, fruit, and gelatin with whipped cream.

C. Suggestions for adding protein:

- Mix small pieces of chopped meat into vegetable dishes, soups, rice or noodle casseroles.

  2 oz. fish = 14 gm. protein
  1/2 chicken breast = 25 gm protein
  3 oz. beef, veal, lamb = 24 gm protein

- Add grated cheese or cream cheese to sauces, casseroles, vegetables. (Ross Laboratories, p. 11-12)

- Finely chopped hard boiled eggs blend easily into sauces, gravies and is barely noticeable. Make desserts that contain eggs--angel food cake, eggnog.

  One egg has 7 gm protein

  (Ross, p. 12)

Examples of Modifications:

Eggnog - "Guggle Muggles" for between meal snacks

1 egg
1 cup milk
2-3 tsp. sugar
1/2 tsp. vanilla        Approximately 300 calories, 15 gm protein

For variation sugar and vanilla substituted with sliced peaches, frozen orange juice concentrate, or frozen strawberries.

Remember these type drinks require a blender. (Rosenbaum, p. 4-58)

Cooked cereals

Substitute water for fortified milk or cream

1/2 cup cereal
1/4 cup fortified milk or cream
1 Tbls. sugar        425 calories/cup

(Helsel)

Soups

High calorie cream of vegetable soup

1/2 cup cooked vegetables (blenderized, mashed, pureed)
1 Tbls. butter or margerine
1 cup fortified milk        350 calories

(Helsel)

D. Commercial products for protein and calories supplementation can be used alone or incorporated into recipes.

Examples of these are granola bars, instant breakfast, Meritene®, Sustacal®, Sustagen®. The lactose free products Cetrotein®, and Ensure® contain less protein and should only be used for lactose intolerant patients.

Examples of how commercial liquid supplements can fortify recipes:

Ensure Pancakes

1 1/4 cups vanilla Ensure® can be added for every 1 cup flour used or prepared mix. (Rosenbaum, p. 4-91)

### Sustacal Geletan Dessert

12 oz. of vanilla Sustacal® liquid or one packet of sustacal® powder mixed with 8 oz. whole milk, can be added to dissolved gelatin in water before chilling. (Mead-Johnson, p. 13)

E. Commercial products for calorie supplementation alone can be easily mixed with normal foods without increasing volume.

Examples:

| | | |
|---|---|---|
| Controlyte | 35 cal/Tbls. | Powder, mix with juices. |
| MCT | 115 | Oil, mix with juices/sauces. |
| Polycose | 32 | Liquid, powder, mix with any food. |

Liquid Polycose can be added to juices, coffee, tea, gelatins. Amount added is equal to amount of water. Powdered Polycose can be added to milk shakes, sauces, gravies without affecting taste of food. (Rosenbaum, 4-91, 3)

Compiled by Mary Daley, RN, MSN

## SUGGESTIONS FOR INCREASING PROTEIN INTAKE

1. Tuna fish snacks (tuna salad on a cracker)

2. Peanut butter on toast rounds or crackers--with apple butter or jelly

3. Homemade soup with a milk base; add meat and vegetables (baby foods may be a useful addition if meat itself is not tolerated)

4. Use double strength milk or fortified milk in anything calling for regular milk (double strength milk = 1 quart of whole milk with 1 cup dried skim milk powder) (fortified milk = 1 quart whole milk + 1/2 cup dried skim milk powder); (lactose-free products and supplements exist for people who do not like or cannot tolerate milk (Isomel®, Ensure® ), lactobaccili enriched milk is available in most grocery stores; a powder which can be added to milk to make it digestible by lactose deficient patients is available at most health food stores and is generally cheaper than milk substitutes.

5. Use instant breakfast powders to make a milkshake

6. Add 1/4 cup skim milk powder and slightly less flour to any baked recipe which calls for flour

7. Add Ovaltine® to milkshakes or milk

8. Add powdered softdrink mixes as flavorings to increase variety of milk drinks

9. Add high calorie, high protein powders (such as Polycose® ) to flavored milk drinks

10. Add strained and junior baby meats and foods to soups and casserole dishes

11. Investigate the use of "junior foods" - they are easy to chew and provide a small serving; be sure to flavor them for adult taste

12. Add wheat germ (plain or flavored) to cereal, meat loaf, snacks

13. Use baby cereal as a fortifier in pancakes, milkshakes, or mix with bread crumbs and use in cooking meat mixtures

14. Deviled eggs are a different taste

15. Blend yogurt with fruit and serve as a mini-meal (buy the yogurt with the highest protein content on the label)

16. Use cheese kisses as snacks

17. Use cocktail weiners or pieces of weiners with toasted buttered bread as a mini-meal

18. Make cheese spreads (cheese with cream cheese, deviled ham, etc.) and serve with crackers or toast

19. Make gelatin milkshakes (1 cup gelatin with 10 ounces milk)

20. Use cooked cereals -- Ralston®, Cream of Wheat®

*Developed by Marian Fedak, R.N., MN.Ed., for Marilee Donovan.

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VIII. Tube Feedings - Contradictory research i.e., effectiveness and nutritional value; may use for giving meds

A. Prepare your patient for the possible need of a tube feeding when severity of anorexia or side effects of disease and/or treatment prevent adequate oral intake. The next section addresses:

1. Criteria for formula selection
2. Criteria for choosing placement of tube
3. Nursing management of tube fed patient

B. Criteria for formula selection - the dietary prescription depends on a patient's ability to tolerate a given diet metabolically and physiologically. This considers renal status, fluid and electrolyte status, medications and underlying disorders. This will require an assessment by a physician and/or registered dietician. The nurse is responsible for being familiar with the needs of the patient and the characteristics of commercial products according to these variables: osmolarity, caloric density, lactose content, viscosity, fat content, taste and expense

1. Osmolarity - carbohydrates plus electrolytes are primarily responsible for the osmolarity of the tube feeding. Osmolarity measures how many particles are present and is not related to ionic charge. Tonicity describes the osmotic pressure of a solution relative to blood plasma. A hypertonic and hypotonic solution have a higher and lower osmotic concentration than plasma respectively.

   This is an important factor in the prevention and management of diarrhea and dehydration.

2. Caloric density - one calorie per cc is considered full strength. In a hypermetabolic state in accordance with patient tolerance, this can be increased to 1.5 kcal/cc.

3. Lactose content - the addition or deletion of milk in supplements may be a critical reason for choosing one product over another. Cancer patients can have an intolerance to lactose secondary to treatment or due to lactose deficiency.

4. Fat content - fat is the most difficult nutrient to digest. The presence of fat in levels above those necessary to prevent essential fatty acid deficiency should be considered in choosing a formula for patients with impaired digestion or absorption. Formulas low in fat or using medium chain triglycerides are appropriate for these patients.

5. Viscosity is a mechanical consideration. The lactose-free, complete nutritional tube feedings are too viscous to flow through a narrow gauge nasogastric tube.

6. Taste - only a factor if taken per mouth. Most manufacturers of supplements have provided flavor packets for their product. They may suggest a popular flavor. Studies have shown that cancer patients do not rank-order a preference consistent with the general population.

7. Expense - these products differ in cost. Using a more expensive product should have a validated benefit for patient. Protein is the most costly ingredient of a formula.

C. Four categories of liquid feedings

   1. Blended tube feedings - foods in the normal diet are blended to a liquid consistency.

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Tolerated well because proportions of carbohydrate, fat and protein are similar to normal diet.

a. Home blended - advantages are that it is inexpensive, patient can vary recipe and become more involved in nutritional care plan. Disadvantages are that they take time and facilities to prepare. Care must be taken to prevent bacterial growth

b. Commercial blended - no preparation or refrigeration necessary. Compleat B is an example; due to its lack of palatability it is used strictly as a nasogastric tube feeding

2. Oral Supplements and tube feedings - these can be used as oral supplements to patients eating solid food or complete tube feedings. Commercial products are nutri-1000, Meritene, Ensure, Instacal and Isocal.

3. Supplemental liquid feedings

a. Lanolac: a high protein, low sodium, low cholesterol powdered food, very close to nutritive value of powdered whole milk. Each quart in normal dilution supplies 20 kcal/fl.oz.

b. Portagen: a nutritionally complete powder which contains medium chain triglycerides and is lactose free. For patients in whom ordinary dietary fats are poorly digested or absorbed and the population of patients who show a lactose intolerance. Each quart in normal dilution supplies 30 kcal/fl.oz.

c. MCT oil: a dietary supplement which contains triglycerides of medium chain fatty acids. One tablespoon (15cc) contains 115 calories. Its use is indicated when conventional long chain

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food fats are not efficiently digested or absorbed

d. Polycose: a glucose polymer high in caloric density but low in sweetness. The powder contains 4 cal./g. Polycose can be added to usual food sources without noticeably changing flavor

e. Controlyte: a dietary supplement of calories only. In normal dilution 370ml provides 1000 calories

4. Elemental diets - also referred to as chemically defined diets or synthetic diets. Most are powders mixed with water to form a hypertonic solution. The nutrients are in their elemental or readily digestable form i.e., amino acids, oligosaccharides or monasaccharides, with little fat. They do not require proteocytic or lipolytic capacity. They are indicated in chronic diarrheal state or those requiring low residue i.e., enterocutaneous fistula. Commercial preparations are Vivonex, Vivonex HN, Precision LR, Precision HN, Flexical. They are 3-4 times more expensive than other products and are much less palatable.

D. Placement sites for entereal nutrition: nasogastric, pharynogostomy, cervical esophagostomy, gastrostomy, jejunostomy

1. Nasogastric Tube - Indications: (a) severe anorexia requiring force feeding; (b) fistula in upper alimentary tract requiring a tube bypassing fistula; (c) malabsorption requiring administration of a formula slowly and continuously; (d) administration of unpalatable formula; (e) short term therapy or when a patient can be taught to remove and insert tube. Contraindications: (a) intractable vomiting; (b) upper gastrointestinal bleeding; (c) patients being threatened with aspiration especially in cases with preexisting pulmonary problem; (d) tracheal intubation imposes

(d) tracheal intubation imposes threat of tracheoesophageal fistula.

2. Pharyngostomy or cervical esophagostomy tube - indications and contraindications of nasogastric route apply. Advantage for long term therapy in that these routes eliminate social and psychological factors faced by a patient with a tube protruding from the nose.

3. Gastrostomy tube - Indications: (a) long term feeding after intestinal surgery resulting in significant malabsorption; (b) obstruction above stomach; contraindications: (a) obstruction below level of stomach or at pyloric sphincter.

4. Jejunostomy tube - Indications: (a) obstruction at a higher level than jejunum; (b) requires low osmolar liquid formula; (c) requires formula composed of medium chain triglycerides due to inadequate mixing of formula with bile salts and pancreatic enzymes.

E. Nursing Management of Intubated Patient: Physical discomfort from tube; patient acceptance of alternate method of feeding

1. Physical discomfort from tube symptoms: sore throat, dry cracked lips from excessive mouth breathing, irritation to nares, maintenance of skin integrity around stoma. Interventions: viscous lidocaine as local anesthetic for sore throat, mineral oil to nostrils to prevent crust formation, alternate nares to prevent tissue necrosis, conscientious mouth care, local skin care where tape is used to anchor tube, prevent leakage of intestinal contents on skin.

2. Patient acceptance of alternate method of feeding

   a. Each patient must be evaluated individually to determine what measures decrease psychological and physiological distress of tube feeding

   b. Determine whether the patient prefers privacy, family involvement or presence of hospital personnel while being fed

   c. Some patients, if dependent on tube feedings as sole alimentation, may want to chew food and then spit it out to be discarded. This enables them to enjoy the taste of food, stimulate digestion and exercise gums to maintain dental hygiene

   d. If tolerated, a cup of coffee, tea, fruit juices or gelatin can be offered to patient to break monotony while being tube fed

3. Complications of enteral hyperalimentation

   a. Mechanical

      - Tube lumen clogged - flush with water or replace tube

- Pulmonary aspiration of stomach contents - check position of tube by air insufflation or roentgenographic examination; administer formula slowly with patient in semi-sitting position

b. Gastrointestinal symptoms - toleration of formula (digestion and absorption) determined by osmolarity of formula, rate of flow and alterations in function and anatomy of gastrointestinal tract. Type and severity of symptoms determine formula composition and type of administration

- Bloating, vomiting - reduce flow rate to prolong time for absorption; ascites not a contraindication, but will decrease volume of formula tolerated

- Diarrhea: etiology determines intervention

  - Large quantity of a hyperosmolar solution causes diffusion of water from villous capillaries of intestine into lumen with resulting distention and diarrhea. This dumping syndrome treated and prevented by keeping flow rate constant around the clock

  - Low serum albumin decreases absorptive capacity of villous capillaries and results in diarrhea. Treatment is to administer a dilute carbohydrate formula to provide for protein sparing and then administer parental albumin

  - Small bowel resection and/or pancreatectomy, partial or total, decreases formula mixing with bile salts and pancreatic enzymes. Use of formula of medium chain tryglycerides reduces resulting diarrhea

- Lactose intolerance requires use of lactose free formula. Severity of symptoms may require use of elemental formula, or reduced concentration and flow rate of presently used formula

4. Minimize nausea/vomiting

   a. Planning

   - Allow the patient an active role in planning what, when and how she/he eats; ideally before nausea/vomiting becomes problematic
   - Adjust times of medications, treatments, nursing care and/or meals to avoid peak times of nausea
   - Plan care procedures to avoid meals to provide relaxed patient
   - Give antiemetic medications before treatments of meals to decrease sensations of nausea and vomiting
   - Round the clock use of antiemetics superior to prn for chronic nausea/vomiting - benadryl, compazine, thorazine
   - 24-28 hours of antiemetic use may be necessary to control nausea
   - Relaxation techniques

   b. Diet

   - Plan diet according to diet history
   - Offer small, frequent meals round the clock to decrease the feelings of nausea and possible vomiting
   - Timing

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- Increase protein/calories in meals/between meals
- Aromas of hot foods may aggravate feelings of nausea when appetite is not normal, so offering sandwiches, salads or other foods may be more appetizing for the patient

c. Emotional factors

- Decrease environmental stressors as much as possible: noise, temperature, procedures, clutter, interpersonal tensions
- Allow the patient to talk about apprehensions and fears or to be silent if desired
- Provide explanations about procedures to decrease anxiety (as appropriate to patient)
- Encourage distractions or others activities

F. Educate patient and family to:

1. Curtail patient body movement as much as possible
2. Sitting up may be more helpful than lying flat
3. Use relaxation techniques to control/prevent nausea as well as to help reduce tension/anxiety
4. Limit oral intake until severe nausea and/or vomiting subsides
5. Take only bland, non-fatty foods
6. Fluids which are palatable and digested with a minimum of GI irritation are warm tea and effervescent drinks

7. Frequent small feedings can decrease feelings of distention
8. Mouth care can decrease sensations of nausea
9. Take antiemetics, tranquilizers or sedatives regularly if nausea is chronic, prn if nausea is intermittant

G. Food preparation to circumvent taste disturbances

1. For patients with decreased taste:
    - a. Meats or fishes flavored with barbecue sauce, teriyaki sauce or smoked sauces
    - b. Encourage highly flavored foods such as pizza, tacos, spaghetti, coffee and mint milkshakes
    - c. Avoid plain meats, fish, poultry, bland casseroles, custards and puddings, plain milkshakes
    - d. Sesame, cheese, herb, carrot or banana breads
    - e. Fresh fruits or vegetables are more flavorful (frozen should be steamed not boiled)
    - f. Flavor boosters:
        - Crisp bacon bits, almonds, ham strips, onions
        - Orange/lemon as garnish
2. For patients with lowered bitter threshold: (i.e., have rancid rotten taste)
    - a. Small portions of meat in casseroles (ground or pureed may help even more evenly distributed with other flavors)

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b. Substitute non-meat proteins

3. For patients with elevated sweet threshold:

   a. Regular desserts have tendency to taste bland

   b. Serve any extremely rich dessert that has several sweet ingredients, i.e., chocolate, coconut, brown sugar or crumb topping, whipped cream topping

   c. Avoid desserts like gelatin or pudding

4. For other disturbances

   a. Dash of salt decreases taste of sweet or acid

   b. Dash of sugar decreases taste of salt

B. Treat stomatitis

1. Oral hygiene

   a. Major principle to success of any regimen is the frequency of administration

   b. Purpose: remove any accumulated debris from the mouth (remove medium for infection), lubricate mucous membranes; soothe oral pain

2. Recommended regimen:

   a. Frequency: oral care should be done every four hours and at HS initially. Frequency increased to every two hours and prn as condition worsens

      - Oral care should be done before meals to freshen mouth and stimulate appetite and after meals to remove accumulated debris

   b. Solution

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- Current debate exists in the literature concerning type of solution to use for oral care
- Mixture of one tablespoon hydrogen peroxide + one tablespoon water + one tablespoon Cepacol®. The peroxide has an oxidizing effect which can help to remove debris, but can be irritating to exposed areas of mucous membranes as can the alcohol in the Cepacol®. (Beck, 1979)
- Mixture of ½ teaspoon salt and one teaspoon soda in a quart of water is effective in removing debris and is generally soothing to mucous membranes, therefore it is more widely recommended. (The alkilinity of this solution is the factor that contributes to its soothing nature.)
- If it does become irritating, may be due to the salt which can then be eliminated from the mixture. (Donaldson, 1977)
- It is most inexpensive and easily obtained
- Commercial mouthwashes should be avoided because most produce a burning sensation due to the astringent qualities in the preparation. They also further dry mucous membranes and upset the balance of the oral flora thus allowing fungal infections to develop. (Trowbridge and Carl, 1975)

c. Mode of administration

- May be used as a mouthwash or gargle
- Warm temperature of the water is more soothing to irritated mucous membranes

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| | • Oral lavage may be necessary as condition of stomatitis worsens - gravity helps to force food particles free without extra oral cavity movements that are required for rinses or gargles. Use IV bag and tubing |
| | 2. Tooth brushing with soft brush and brushing dentures: |
| | a. Importance of good brushing is that dental plaque is a causative agent in inflammatory lesions of the gingiva. The bacteria formed activates enzymes and acids which attack the tissues |
| | b. Brushing also helps to stimulate the gingival tissues for better circulation to the area |
| | c. Should be done after every meal and at HS |
| | d. Wearing of dentures will irritate stomatitis so should not be worn. If patient does wear dentures for meals only, should be cleaned as indicated |
| | 3. Use of the Water Pik®. Use with care, always on low |
| | a. Helps to remove particles between the teeth |
| | b. Stimulates circulation to the gums |
| | c. Use a low pressure setting only to prevent initiation or exacerbation of gingival hemorrhage |
| | d. Slight gingival bleeding with brushing or Water Pik® not be interpreted as a signal to immediately discontinue regimen, but should become less as good oral care leads to healthier tissues |

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| | e. Any increase in the slight bleeding should be reported to the physician and the regimen discontinued until further orders are received<br>4. Care of the lips<br>a. Lubricating action of petroleum based jelly like Vaseline® helps to soothe dry, cracked lips (Beck, 1979)<br>b. Humidifier in the room especially for those patients who may be "mouth-breathers"<br>5. Management of candidiasis (thrush)<br>a. Candida albicans<br>b. Candida albicans can be found on normal skin, on oral and genital mucosa and in stools of healthy persons<br>c. An altered oral environment in cancer patients frequently allows overgrowth of candida albicans<br>● Oral environment can become altered as a result of the disease and/or treatment<br>● There is an increased susceptibility to candidal infection in neutropenia and when patients receive broad spectrum antibiotics<br>● Supra infection following antibiotics and steroids (Williams, 1977)<br>d. Treatment of candidal infections<br>● Rinsing with 2cc of Mycostatin 100,000 u/cc QID<br>● Or, dissolve Mycostatin suppository in mouth (lozenge) to allow a constant |

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supply of the antifungal agent

- Solution of 1:1000 Benzalkonium Chloride solution may also be effective for persistent infections (Bottomley, et al., 1977)
- Effective regimen for controlling candida ulcerations is alternating rinses of 2cc Nystatin oral suspension, alkaline saline solution, and 0.5% povidone-iodine solution with two hour intervals between rinses (Bottomley, et al., 1977)
- Prophylactic antifungal agents have no impact on future development of thrush. Oral anticandidal therapy should be reserved until there is clinical evidence of infection (Williams, 1979)

6. Assessment and control of oral pain

   a. Oral pain interferes with: ability to eat (malnutrition) and successful oral hygiene (infections)

   b. May need local anesthetics and analgesics for pain control prior to oral care and meals

   - Viscous zylocaine is a commonly used local anesthetic for the oral area
     - Should be administered ½ hour before meals
     - May be administered alone or diluted with water
     - Instruct patient to "swish and hold" medication in mouth for 3-5 minutes. May expectorate or swallow medication

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- Many patients prefer applying it only to the sorest areas which minimizes the risk of burning and/or the loss of taste

- Effects of medication last approximately ½ hour
- Caution patient regarding extremely hot or cold foods when using an oral local anesthetic because they may receive burns without realizing it
- Unfortunately, this medication interferes with normal taste perception

c. Tylenol® Elixir

- May be "swished" in mouth and swallowed for local and systemic pain relief

d. Systemic analgesia may be necessary (See Pain)

e. Always determine effectiveness of pain measures instituted and initiate other appropriate measures when indicated

7. Modify diet

a. Bland diet usually tolerated best

b. Encourage diet high in calories and protein to meet energy requirements of the cell and facilitate healing

c. Encourage in-between meal supplements

d. Cold foods may be more soothing to the oral cavity than warm (i.e., popsicles, ice-cream)

e. For patients with xerostomia (absence of saliva), liquids, pureed foods or very soft foods are tolerated best. In general, highly seasoned and acidic foods are not tolerated well

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SECTION D: PROBLEMS OF ELIMINATION

I. Anatomy of Small Intestine

   A. 20 ft. in length; divided into duodenum, jejunum, and ileum

   B. Main function is absorption; surface area serves an absorptive function which is increased by:

      1. Pilae circularis - these are permanent transverse folds which increase surface area for absorption

      2. Villi - fingerlike projections responsible for absorption

      3. Microvilli - processes on free surface of epithelial cells that form brush border

II. Anatomy of Large Intestine

   A. 4-5 ft. long; divided into ascending, transverse, and sigmoid colon

   B. Chief function is concentration and storage of fecal material

   C. Characteristics of intestinal wall (from outside in):

      1. Serosa

      2. Longitudinal (taenia coli)

      3. Circular (contraction of the circular muscle contributes to haustra)

      4. Submucosa

      5. Mucosa

III. Innervation of Large and Small Intestine

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A. All motor activity is performed by the smooth muscle except at the anal end

B. Sympathetic

  1. Efferent fibers from the celiac and mesenteric plexus innervate the small intestine

  2. Efferent fibers from the superior mesenteric plexus innervate the cecum, appendix, ascending colon, and transverse colon

  3. Efferent fibers from superior and inferior hypogastric plexus innervates the descending and sigmoid colon and rectum

C. Sympathetic excitation inhibits contraction of smooth muscle but excites ileocecal valve and internal anal sphincter

D. Parasympathetic

  1. Efferent innervation to small intestine, cecum, appendix, ascending, and transverse colon is by way of vagus nerve to myenteric plexus

  2. Efferent innervation to the descending and sigmoid colon is by way of the hypogastric plexus which ends in the myenteric plexus (rectum also)

E. Increased activity of the parasympathetic leads to excitation of the intestine

F. Hypothalamus is higher brain center involved in mediation (Davenport, 1977)

IV. Motility of Small Intestine

A. Segmentation

  1. Relaxation and contraction of smooth

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muscle dividing chyme into segments to continually bring it to surface of intestine for absorption

- B. Peristalsis
  - 1. Stimulated by distension; a progressive wave of contraction advancing steadily forward pushing fecal mass

V. Motility of Large Intestine

- A. Haustrations
  - 1. Nonprogressive contractions of circular muscle which fold mucosa into sacs; these form and reform at different sites producing a kneading type of movement which facilitates water absorption
- B. Segmental propulsion
  - 1. Displaces contents of intestine from one haustra to next
- C. Mass propulsion
  - 1. Movement of feces large distances; occurs 2-4 times per day usually after meals
  - 2. Movement in large intestine is slow

VI. Absorption

- A. Absorption of most foodstuff takes place in small intestine
- B. Large intestine absorption consists of:
  - 1. Active absorption of sodium and passive absorption of water
- C. Passively secretes potassium and bicarbonate
- D. The majority of these exchanges occur in the ascending and descending colon

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E. Colon has the capacity to absorb 460mEq of sodium/day and 2,000ml of water

VII. Defecation

A. Contractility and motility of intestine increases after meals due to distension by food (gastroileal reflex increases contractile activity of ileum which relaxes ileocecal valve allowing food [chyme] through)

B. Normal stimulation of defecation is sudden distension of walls of rectum produced by the entrance of feces

C. The reflexes mediated by nerve plexus and reinforced by external nerves to terminal end of large intestine

D. Contraction of rectum yields relaxation of internal and external sphincters (the internal sphincter is comprised of smooth muscle and the external sphincter is comprised of sketal muscle and is under voluntary control.) There is also an increase in peristalsis in sigmoid colon propelling feces through anus

E. All of the above is assisted by deep inspiration followed by closure of glottis and contraction of abdominal muscles and chest muscles (Valsalva maneuver) causing an increase in intra-abdominal pressure (with a concurrent increase in intrathoracic and blood pressure)

F. Higher brain centers (hypothalamus) can override afferent input from rectum to keep external sphincter closed

G. If defecation does not occur tension in the wall decreases as muscle relaxes and urge to defecate subsides until next mass movement pushes more feces into rectum increasing volume and eliciting reflex

VIII. Contents of Stool

A. Receives 500cc of chyme from small intestine per day

B. Contains mucus, desquamated cells, bile salts, and enzyme secretions of upper digestive tract with undigested food residue

C. Most of digestable food (CHO, fat, and protein) as well as large amount of water (200-400ml per hour) is absorbed in small intestine (Davenport, 1977; Vander et. al., 1975; Mountcastle, 1974; Bockus, 1976).

IX. Colostomies

A. Usually performed for carcinoma or obstruction (in large intestine)

B. Different types can be performed throughout large intestine

C. The higher up in the intestinal tract, the more liquid the stool will be

D. Colostomies that can be controlled through irrigation are those in the descending or sigmoid colon

E. Application of all principles in dealing with diarrhea and constipation apply to colostomies unless noted otherwise

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| | X. Nursing Assessment<br>A. Obtained and incorporated into patient's plan of care<br>B. Patient should be allowed to continue his routine as much as possible to avoid complications<br>1. History of elimination (time, problems)<br>2. Medications currently taking and in the past<br>3. Usual food patterns: recent and changes<br>4. Recent changes in bowel habits<br>5. Characteristics of stool<br>6. Laxatives/what patient takes for constipation or diarrhea (Jones et al., 1978) or has taken in the past<br>XI. Constipation<br>A. Defined as feces occuring with insufficient frequency, being of insufficient quantity or being very hard and dry<br>B. Causes<br>1. Ignoring of defecation reflex - too much energy needed or too painful<br>a. Water absorption is increased causing hard stool; loss of reflex can occur<br>2. Decreased fluid intake<br>a Absorption of water from intestine increases in order to maintain fluid balance of body<br>3. Hypomotility |

   a. Occurs via sympathetic stimulation which decreases peristalsis

   b. Narcotic usage (there is also a loss of the defecation reflex)

   c. Pain, fear, anxiety, depression (pain also causes a decrease in defecation reflex)

   d. Some chemotherapy - especially Oncovin (Vincristine)

   e. Antacids

   f. Diuretics, sedatives, tranquilizers, antidepressants

4. Hypokalemia

5. Manipulation during surgery

6. Decreased food intake

   a. It is important to realize that a decrease or very little food intake will effect the amount of stool in the colon. However, stool also consists of previously mentioned products, therefore, patients with little food intake are prime candidates for impactions (Lamerton, 1976)

7. Elimination - high fiber

   General Rules for increasing roughage in the diet

   a. Replace soda pop and other beverages with fruit juices with pulp

   b. Replace convenient snack foods with nuts, seeds and raisins

   c. Replace cooked and canned fruits and

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and vegetables with ones that are unpeeled and raw

d. Use dried fruits, peas, beans, lentils

e. Use whole grain cereals instead of refined or sugar coated cereals

f. Use whole grain flour products instead of refined flour or flour products

XII. Impaction

A. Defined as an accumulation of hard or soft stool in intestine which is unable to be passed (Lewin, 1976)

B. Signs and symptoms

1. Oozing stool and patient unable to recall when last bowel movement was

2. Can occur in colostomy

3. Complaints of bloating, anorexia, lethargy, distension

4. Bowel sounds are usually normal

5. Rectal exam reveals fecal mass in rectum (unless impaction is higher in intestine) (Jones et al., 1978)

C. Treatment

1. Oil retention or saline enemas to clean out bulk

2. Digital breaking up may be needed

3. Laxative to stimulate movement of fecal material higher up in intestine

4. Patient may need enema on the next day if all of impaction is not removed

5. Assess patient's condition throughout enema giving; they are very fatiguing (Lewin, 1976)

D. Prevention

1. Supply diet with indigestible residue
2. Supply diet with fluid intake
3. Exercise: 15 minutes/day
4. Establishment of habit of defecating at same time
5. Assist with emotional factors

E. Bowel Routine

1. Utilized for people who have a decreased defecation reflex or decreased bowel motility due to drugs, nerve damage, age, or psychological upsets
2. Each person has his own pattern and this must be ascertained; a bowel movement everyday is not "normal"; if no pattern has been established it is wise to check for stool on every third day and give enema if needed
3. Diet can be supplemented with stool softeners or bulk laxatives
4. A glycerin suppository or Ducolax suppository may be used to stimulate bowel movement. Use on day #3
5. A Fleet or saline enema may be needed if a suppository does not work (the use of soap suds or repeated tap water enemas are harsh and may cause electrolyte depletion). Use on day #4
6. Whenever possible the patient should be assisted to toilet or commode--this

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| | assists in increasing intra-abdominal pressure and gravity to move feces out<br>7. If a patient is ambulatory, establishing a pattern of sitting on the toilet at the same time each day and drinking some coffee or prune juice may be sufficient to initiate a pattern of regularity<br>8. Bedridden patients should be encouraged to tighten and relax abdominal muscles if able, to decrease loss of muscle tone<br>9. Although bedpans are not conducive for bowel movements, if they are used, the head of the bed should be elevated and a pillow placed at the small of the back (straining is increased with bedpan) (Lewin, 1976; Jones, 1976; Pollman, 1978; Sine et al., 1977)<br>XIII. Laxatives: Use on day #5 if no defecation<br>A. From Latin, laxativus meaning loosening<br>B. All of the laxatives to be discussed work on on large intestine unless otherwise noted--the most popular ones will be discussed<br>C. Stool softeners<br>1. Colace, Surfak<br>a. Felt to decrease surface tension which is thought to facilitate penetration of stool by water and fats<br>b. Softens in 24-48 hours<br>c. Use of 50-480mg/day (larger doses may be needed at first and then decreased)<br>2. Mineral oil<br>a. Softens stool by retarding reabsorption of water |

   b. 15-45ml before bed is usual dosage

   c. Not to be used frequently as it interferes with absorption of fat soluble nutrients

D. Bulk forming laxatives: Metamucil®, bran

   1. These substances dissolve and swell in water to form gel to maintain feces soft

   2. This increased bulk which increases peristalsis and increase transit time

   3. Effective in 2-3 days

   4. Metamucil® dose: 1-2 tbsp. 1-2/day

   5. Bran: must take at least 6 tsp./day to be effective

   6. Lots of fluids must be given with these

   7. Ideal for people who have decreased food intake

E. Saline cathartics: Mg salts (Epson Salts), Magnesium Citrate, MOM

   1. These are slowly absorbed from the intestine and retain water in the colon by osmotic forces

   2. Not to be given to patients with a history of kidney problems (due to the salts)

   3. Watch for excess water loss

   4. Dose of 15cc usually effective in 3-6 hours and yields a semifluid evacuant

   5. Stimulates both the large and small intestine

F. Stimulant cathartics

   1. Castor oil

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|  | a. Effects small intestine |
|  | b. Increase mucous secretion due to its irritating effect |
|  | c. Can cause abdominal pain |
|  | d. There is excess fluid evacuation with laxatives |
|  | 2. Ducolax (oral and suppository), cascara, senna (Senokot) |
|  | a. These stimulate myenteric plexus |
|  | b. Act on large intestine with effects in 6 hours |
|  | c. Ducolax suppository stimulates colonic peristalsis |
|  | 3. Glycerine suppository |
|  | a. Have mildly stimulant and lubricant properties |
|  | b. May not be as effective in stimulating bowel (Goodman & Gilman, 1975; Jones & Godding, 1976) |

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XIV. Diarrhea

- A. Occurs when a large amount of fluid entering from the small intestine overwhelms the large intestines capacity to absorb water and electrolytes or when absorptive capacity of colon is reduced
- B. The main treatment here is to correct the underlying problem
- C. Some causes of diarrhea
  - 1. Antibiotics
    - a. Cleocin, Ampicillin, Kanamycin, Tetracycline
    - b. Due to change of normal intestinal flora
  - 2. Radiation treatment to abdominal area
  - 3. Excitement or anxiety states
  - 4. Intestinal flu
  - 5. Illness
  - 6. Generalized weakness
- D. If underlying problem can not be solved measures can be taken to help palliate diarrhea
  - 1. Place on low residue diet
    - a. If very severe patient may need to be placed on elemental feedings
    - b. Vivonex Precision LR
    - c. In some cases Parental Alimentation may be necessary

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|  | 2. Rest to decrease bowel motility<br>3. Use of antidiarrheal meds<br>a. Meds containing kaolin or pectin (Kaopectate)<br>• Kaolin is thought to act as an absorber and also absorber of bacteria<br>• Possibly give more bulk to stool<br>b. Tincture of Opium, Paregoric<br>• Derivatives of opium/morphine<br>• Causes a decrease of propulsive peristaltic waves<br>• Tolerance may be acquired (varies patient to patient)<br>• Dosage of Tincture of Opium .6-1.5cc<br>• Dosage of Paregoric is 5-10cc<br>c. Lomotil<br>• Meperidine congener with constipating effect<br>• Dosage is 20mg in divided doses<br>d. Immodium<br>• Has little residual CNS activity<br>• Inhibits small bowel activity<br>• Dosage is 2mg b.i.d. (Goodman & Gilman, 1975; Paterson, 1977) |

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| | E. Patient care measures<br>1. Cold liquids tend to stimulate bowel activity so offer warm liquids<br>2. If patient is to be placed on supplemental nutrition, check for lactose intolerance since many of these liquids are milk-base<br>a. 50% adult population is lactose intolerant so assess amount of pudding etc. eaten<br>3. Keep bedpan or commode nearby<br>4. Check for anal excoriation due to liquid stool; use careful cleansing after each movement; application of local anesthetic or warm sitz baths may provide relief<br>5. Monitor fluid and electrolyte balance<br>a. Mild loss; dry mucous membrance and weight loss<br>b. Moderate loss: poor skin turgor, thirst<br>c. Severe loss: symptoms due to a low potassium (weakness, lethargy, decreased or absent deep tendon reflexes) (Donovan & Pierce, 1976; Jones et. al., 1978) |

SECTION E: INCONTINENCE

I. Anatomy and Physiology of the Bladder
(Gittes, Harrison, Perlutter, Stumer and Walsh, 1979; Guyton, 1978; Smith, 1978)

A. Musculature

1. The major portion of the bladder's body is composed of smooth muscle, the detrusor muscle

2. The trigonal muscle is located at the mouth of the bladder between the openings of the two ureters and the opening of the internal urethra opening

3. Sphincters

a. the internal sphincter, composed of smooth muscle, is located at the junction of the urethra and the bladder. It keeps the urethra closed until micturation

b. the external sphincter, composed of skeletal muscle, is immediately below the prostrate in men and in the middle third of the urethra in women. It maintains tonic contractions until voiding

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B. Nerve Innervation--Non-Voluntary Control of Micturation

1. Stretch receptors located in the bladder wall are stimulated by the accumulation of approximately 300ml of urine in the bladder (Greisheimer & Wiedeman, 1972, pp. 521)
    a. Impulses travel to the sacral segment of the spinal cord through the pelvic nerves by parasympathetic pathways
    b. When bladder contractions begin some relaxation of the internal sphincter occurs
    c. Within a few seconds to a minute, this reflex starts to fatigue and may not start again for another hour
2. Pudendal nerve endings in the external sphincter are stimulated by the flow of urine in the urethra
    a. Impulses from the nerve endings travel to the first two segments of the sacral segment
    b. During the micturation cycle the external sphincter relaxes
3. The sympathetic nerves supply the bladder wall and the internal sphincter. These nerves inhibit bladder contractions until voiding occurs

C. Voluntary Control of Micturation

1. Impulses of the bladder filling travel from the sacral segment of the spinal cord to the midbrain and cerebral cortex

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a. The central nervous system inhibits urination by maintaining continuous tonic contraction in the external sphincter

b. The central nervous system facilitates micturation by inhibiting external sphincter contraction

2. Normal micturation under voluntary control occurs with bladder contractions and simultaneous relaxation of the sphincters

II. Bladder Disorders

A. Spastic Bladder (Reflex or Automatic) - bladder empties without warning. Causes include:

1. The spinal cord is damaged above the sacral region, but the sacral segment is intact. The micturation reflex occurs, but there is no control by the brain

2. Examples: spinal tumors and vetebral metastases with cord compression; radiation, neuropathy

B. Flaccid (Atonic, Nonreflex, and Autonomous) Bladder--the bladder fills to capacity without the sensation of fullness. Causes include:

1. Sensory nerve fibers from the bladder to the spinal cord are destroyed, which leads to inadequate, unsustained contractions to completely empty the bladder. Finally the pressure within the bladder reaches its maximum limit, exceeding the urethra pressure and a small amount of urine flows to decrease this pressure difference. (Guyton, 1978 & Smith, 1978)

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2. Occurrence of tumor, surgical trauma to sacral region

C. Unhibited Neuropathic Bladder--Patient has the desire to void but cannot prevent urination long enough to reach the bathroom (Smith, 1978). Causes include:

1. Interruption of inhibitory signals causing frequent and uncontrolled urination (Smith, 1978)

2. Occurence of brain tumor, vetebral prolapsed lumbar disc

III. Types of Incontinence

A. True Incontinence--the loss of urine through an opening with no control. This is seen in persons with vesicovaginal fistula, neoplasms, or injury to the urethral smooth muscle sphincter during radical prostatectomy

B. Stress Incontinence--the loss of urine during some type of stress (as coughing, laughing, sneezing, standing) due to weakness in the sphincter mechanism and muscle tone of the pelvic floor -

1. Stressful events increase the pressure in the bladder and the weakened sphincters and muscle tone are incapable of holding the urine (Cantor, 1979)

2. Stressful events include coughing, laughing, sneezing, sitting and standing

C. Urgency Incontinence--the desire to void comes so quickly the person can not reach the bathroom before voiding

1. Seen in persons with upper motor lesion, tumor, or urinary tract infection

2. Occurrence may be caused by the same

mechanism involved with the unhibited neuropathic bladder

3. When inflammation is present the over-stretched inflamed muscle may spasm (Priscilla, 1979)

D. Paradoxical Incontinence--a small amount of urine flows occasionally or constant dribbling occurs

   1. Seen in persons with urinary retention, secondary to flaccid bladder, lesions and obstruction

   2. The bladder overfills creating greater pressure than the urethral pressure which allows some urine to escape relieving the pressure within the bladder (Smith, 1978)

E. Several types of incontinence can exist simultaneously

IV. Methods to Control Incontinence

A. Indwelling Catheter

   1. Only a temporary measure to control incontinence because of increased risk from long term use

   2. Advantages

      a. The catheter is constantly draining urine from the bladder

   3. Disadvantages:

      a. Increased risk of urinary infection because of bacteria ascending in the tubing (Barrows, Jameson, & Lange, 1976)

      b. Bladder spasms may occur from irritation caused by the catheter

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   c. Pyelonephritis can develop due to urine reflux (Jacobs & Kaufman, 1978)

   d. Formation of urethral fistulas, diverticula, and strictures caused by the pressure of the catheter upon the urethra (Jacobs & Kaufman, 1978)

   e. Calculi can form in the bladder

   f. Interference with sexual activities

   g. Increased risk of developing bladder carcinoma if used over ten years (Fam, Gabilondo, Jacobs, Kaufman, Pkane, Rossier, & Yalla, 1978)

4. Catheter Insertion and Maintenance

   a. Insert catheter using aseptic technique

   b. Do not clamp catheter:

      - to prevent overdistension of the bladder. This leads to decreased blood flow to the bladder which inhibits the ability to fight infection (Champion, 1976)

   c. Employ asceptic technique

      - Roll catheter between fingers to determine if sediment is obstructing catheter. (Sometimes sediment may obstruct catheter at the tip)

      - If obstructed, remove catheter and replace it, instead of irrigating (Irrigation could push the bacteria back into the bladder)

5. Drainage Bag

   a. Should be a closed drainage system to limit bacteria entering into the system

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through air contamination

b. Should have a valve to prevent urine reflux

c. Should not come in contact with the floor because the drainage port may become contaminated

d. Special care is needed when emptying the bag

  - Hands should be washed after emptying each bag to prevent cross contamination

  - Should have a separate emptying container for each patient

e. Separate patients with urinary tract infection from other patients

f. The drainage bag and tubing should be lower than the bladder to facilitate drainage by gravity (to prevent urine stasis in the bladder and reflux). Avoid loops or kinks in the tubing

g. Leg bag--catheter drains into a small bag strapped to the leg

  - Do not strap it tightly otherwise it will decrease circulation to the leg

  - It needs to be emptied more frequently than the overnight drainage bag

  - It is easy to conceal under clothing

  - An ambulatory patient can use the leg bag during the daytime and use an overnight drainage bag at night

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- Select a leg bag which has a valve to prevent urine reflux

6. Catheter Care

   a. Wash the area around the catheter with soap and water. Then starting at the catheter insertion site apply an iodophor solution in a circular outward movement. Follow this with an application of an iodophor ointment two to three times a day

   b. If the patient is allergic to iodine, clean area with soap and water and apply an antibiotic ointment to the meatus

7. Bladder spasms caused by the irritation of the catheter

   a. Give appropriate antispasmodic agents

B. Intermittent Catheterization

1. Advantages:

   a. One means to control incontinence over a long period of time

   b. The infection rate is lower with intermittent catheterization compared to indwelling catheter because there is no urine reflux from the catheter tubing, therefore there is no route for bacteria to travel and trauma is minimized (McMaster, Nicholas, & Rosen, 1978)
   Use asceptic technique in hospital

   c. It allows the patient to remain sexually active

   d. It can be used with bladder training exercises

      - Indwelling catheters inhibit sphincter contraction

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| | e. There is a decrease in irritation to the bladder and the urethra<br>f. There is a decrease in fistula formation trauma<br>g. The patient can learn to perform the procedure using a clean technique |

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2. Disadvantages

    a. Infection can be caused by the introduction of bacteria during catheterization

    b. Damage to the urethra can occur during catheterization

    c. Hydronephrosis can occur because of large residual or infected urine refluxing (Carter, David, & Pelosof, 1977)

3. Procedure

    a. Have the patient attempt to void using the Credé maneuver, then catheterize the patient with a #12 or #14 French catheter every four hours

    b. Measure residual urine; if it is below 200 ml for 24 to 48 hours decrease frequency of catheterization to every six hours. This can be progressively reduced to every eight and then 12 hours if the residual urine remains under 200ml for 24 hours (Champion, 1976; and Hartman, 1978)

    c. The sterile technique should be employed by nurses to prevent hospital acquired infections

    d. Self catheterization can be taught to the patient to perform at home

        - Use the clean technique in the home

        - The infection rate is not

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increased when the patient uses the clean technique compared to sterile technique in the home (Champion, 1976). The patient is not exposed to all the bacteria found in the hospital

e. Limit fluid intake to 1500-2000ml per day to help control the frequency of catheterization (Hartman, 1978) yet maintain adequate flow

C. Suprapubic Catheter

1. The catheter is inserted directly into the bladder from the suprapubic area

2. Advantages:

   a. No urethral trauma occurs since the catheter does not enter the urethra

   b. There is a reduction in bacteria since no urethral trauma occurs which is associated with higher incidence of infection (Donovan & Kiviat, 1977)

   c. The cost is reduced compared to intermittent catheterization

3. Disadvantages:

   a. Difficulties in maintaining patency can occur because of sediment blocking the tubing

   b. Infection can be caused by the bacteria ascending the tubing

   c. Dribbling from the urethra may occur

   d. Bladder spasms caused by the catheter irritating the bladder have occured

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4. Patient Care

    a. Keep insertion site clean with daily application of an iodophor solution

    b. Periodic changing of the suprapubic catheter will be needed to reduce the risk of infection. (Recommended time varies from every month to every few months)

5. Evaluating for obstruction

    a. The catheter tip may be lying against the bladder wall. Have the patient turn side to side to move the tip away from the wall (Wiley, Wilsey, and Woodrow, 1976)

    b. Check tubing for kinks

    c. Milk tubing to dislodge sediment

D. Condoms--an external device around the penis secured by adhesive. There are many different types commercially available

1. Advantages:

    a. There is no urethral trauma

    b. Risk of infection to the urethra and bladder is reduced since there is no urethral trauma or catheter directly entering the bladder

2. Disadvantages:

    a. Damage to the skin from removing adhesive may occur

    b. There may be irritation to the skin caused by the exposure to the urine

    c. There may be difficulties in keeping

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the device on

d. If the device is applied tight, it will decrease the blood flow to the penis and cause necrosis

e. Not possible for female patients

3. Patient Care

   a. Shave the pubic hairs which might adhere to the tape

   b. Wash the penis with soap and water and rinse well prior to applying the device

   c. Dry the skin carefully. Do not rub, otherwise further damage can occur

   d. Apply a skin barrier to prevent skin irritation especially when applying adhesive directly to the penis

   e. Apply the device as the manufacturer recommends

   f. Tape the device to the thigh so twisting does not occur. (allow for some slack so the patient does not dislodge the device when moving)

   g. Change the device every other day and allow the penis to be exposed to air; this will decrease moisture buildup which acts as a good medium for bacteria

E. Prosthesis--An instrument (usually a silicone cuff) is surgically placed into the perineum which applies pressure around the urethra to control urination (Worth, 1979)

   1. It works by inflating the cuff to prevent urination and deflating the cuff to allow

for urination. The point is located under the skin in the abdomen for women and in the scrotum for men (Cantor, 1979 & Scott, 1978)

2. Advantages:
    a. This is one method to control incontinence without an external device or catheterizations

3. Disadvantages:
    a. It requires surgery
    b. The pressure around the urethra can lead to necrosis
    c. Cost

4. Patient Care
    a. The amount of pressure used in inflating the device must be carefully watched to prevent necrosis (Cantor, 1979)

F. Electronic stimulators (experimental)--an electronic device to enhance sensory awareness of a full bladder and of the ability to contract the perineal and pelvic floor muscles (Cantor, 1979 & Smith, 1978)

1. Advantages:
    a. The electrodes are disposable and the generator is relatively inexpensive
    b. It is externally or internally located. (examples: Introvaginal and anal devices)

2. Disadvantages:
    a. Sometimes the device is worthless for long-term use

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

 b. Intravaginal devices are not easily removed which can lead to sexual frustration (Cantor, 1979)

 c. Vaginal and cervical inflammation can occur from the device irritating the vaginal wall or cervix (Cantor, 1979)

 d. The device may fall out

 e. Damage to the device can occur

 f. The anal devices need to be removed for defecation and cleaned frequently to work properly

3. Patient Care

 a. Exercises can be used to help strengthen the perineal and pelvic floor muscles which may return the patient to normal voiding patterns

 b. The device needs to be removed for cleaning, especially anal devices

G. Penile clamps--padded metal device applied around the penis to apply pressure to the urethra (Smith, 1978)

1. Advantages:

 a. This is one way to control dribbling

 b. The patient can use a condom while at home and use the clamp when going out

2. Disadvantages:

 a. When the device causes too much pressures against the urethra, necrosis can occur (Baumrucker, 1979)

 b. Sometimes it is an ineffective means of controlling dribbling

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

    c. It is difficult for the patient to apply the device correctly

  3. Patient Care

    a. Remove and change position of the clamp about every two hours to prevent decreased circulation to the area and to allow for voiding (Willington, 1976)

    b. Do not apply tightly, otherwise urethral trauma and necrosis can occur

H. Incontinence pads

  1. There are commercial incontinence pads available with plastic lined underwear. Sanitary pads can be used by female patients with a small amount of dribbling or stress incontinence

  2. Advantages:

    a. No urethral trauma can occur

    b. There is a lower risk of infection to the bladder

    c. Bladder exercises can be performed

  3. Disadvantages:

    a. Skin excoriation is caused by the exposure of moisture and urine to the skin

    b. Bulky pads are uncomfortable and may be undesirable to the patient

    c. Incontinence pads are expensive for long-term use

    d. Problems with odor control will occur

  4. Patient Care

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | a. Apply skin barriers to protect the skin<br>b. Keep area clean<br>c. Allow the air to come in contact with the skin for 15 minutes every eight hours<br>d. Check the patient every hour to determine if pads are soiled when the patient is unable to do this<br>V. Other Measures to Control Incontinence<br>A. Bladder exercises--to help strengthen weaker sphincters, perineal and pelvic floor muscles (Cantor, 1979)<br>1. Exercises cannot be performed correctly if there is an indwelling urethral catheter. The catheter inhibits sphincters' contraction (Cantor, 1979)<br>B. Infection Prevention<br>1. Infection can aggravate incontinence<br>2. Fluid intake should be about 2,000cc per day<br>3. If the patient voids infrequently and large amounts of urine accumulate, encourage more frequent urinations to prevent the pooling of urine in the bladder which acts as a medium for bacteria growth<br>4. Instruct the female patient to clean after each voiding and bowel movement from front to back to prevent contamination from the bowel and vagina<br>VI. Some Types of Surgeries to Correct Urinary Incontinence |

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

A. Ileal Conduit--the ureters are anastomosed to a portion of the ileum which is brought to the surface of the abdomen to form a stoma. An appliance over the stoma must be worn continuously to collect the urine (Gittes, et al., 1979)

1. It is used to manage incontinence and carcinoma of the bladder

2. Advantages:

   a. Only one appliance is worn

   b. Fewer problems develop after surgery compared to other diversions

3. Complications:

   a. Obstruction

   b. Stoma stenosis (Althausen, Mitchell, Pfister, & Yoder, 1977)

   c. Pyelonephritis (Gittes, et al., 1979)

   d. Calculi formation

   e. Skin irritation around the stoma (because of urine leakage, allergies to the adhesive or improper removal of appliance)

   f. Trouble keeping appliance on

   g. Altered body image

4. Patient Care

   a. Follow systematic, planned procedure for removal and re-application

   b. Adhesive should be removed from appliance and washed with soap and water

c. To reduce odor soak appliance in a mixture of one quart of water and one tablespoon of vinegar

5. Observations of the stoma

a. Observe for prolapse or retracting stoma and report abnormal findings to the physician

b. Report any abnormal bleeding which does not readily stop

c. Observe for necrosis, obstruction or skin irritation

B. Cutaneous ureterostomy--the ureters are brought to the surface of the abdomen and an appliance is applied over the ureters (Gittes, et al., 1979)

1. It is usually seen in patients with limited prognosis and with neoplastic obstructions

2. Complications:

a. Ureters tend to slough or form strictures

b. There are difficulties with keeping an appliance on

c. Two appliances are needed

3. The care is similar to that of the ileal conduit

C. Urethrosigmoidostomy--the ureters are anastomosed to the sigmoid colon where the urine and feces become mixed. (The patient needs to have a good anal sphincter.)

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | 1. Advantages:<br>a. No appliance is needed<br>b. There is no drastic changes in body image<br>c. It is less expensive since the patient does not have to buy an appliance<br>2. Complications:<br>a. There is free reflux of feces to the kidneys (Gittes, et al., 1979)<br>b. Stenosis and obstruction occur<br>c. Electrolyte imbalances caused by the bowel reabsorbing electrolytes excreted in the urine can occur (Gittes, et al., 1979)<br>d. These patients have a higher risk of developing carcinoma of the colon (Leadbetter, Piece, and Zickerman, 1979)<br>3. Patient Care<br>a. The patient needs to learn to defecate every four hours during the day and once in the night to prevent hyperchloremic acidosis and hyperkalemia (Gault, 1977)<br>b. Watch for signs of hyperkalemia<br>- Neuromuscular symptoms: weakness; occasional paralysis; loss of deep tendon reflexes; irritability and confusion<br>- EGG changes |

- Respiratory paralysis

c. Watch for signs of hyperchloremic acidosis

- Stupor
- Deep, rapid breathing
- Weakness
- In severe acidosis--unconsciousness

D. Cutaneous vesicostomy--the bladder wall is brought to the abdominal wall in which a small opening into the bladder is constructed like a stoma (Gittes, 1979)

1. It is performed when the bowel cannot be used for an ileal conduit or when the patient cannot tolerate a long surgical procedure

2, Advantages:

a. No urethral trauma/damage occurs

3. Complications:

a. There are difficulties with keeping an appliance on

b. Stoma stenosis can occur (Brady, Foret, Mebast, & Sloss, 1971)

c. Calculi can form

d. Bladder dilation may develop (Brady, et al., 1971)

e. Prolapsed bladder through the stoma can occur (Brady, et al., 1971)

f. The bladder is unable to contract to force urine out and the residual urine acts as a medium for bacterial growth (Brady, et al., 1971)

g. Urine leakage from the urethra can occur

E. Continent Vesicostomy--the urethra is surgically closed and an external nipple valve is made from the bladder wall which is brought to the surface of the abdomen (Barrett, 1979)

1. It is currently used in an areflexic bladder, otherwise bladder spasms can occur

2. Advantages:

    a. No external appliance is needed, only a 4" x 4" is needed to cover the area

    b. There is no urethral trauma

3. Complications

    a. The major problem is nipple dysfunction (Barrett, 1979)

    b. There is a risk of infection through the introduction of a catheter

4. Patient Care

    a. The patient can use the clean technique to catheterize him/herself through the nipple

    b. The self catheterization needs to be performed four to six times a day (Barrett, 1979)

    c. Limit fluid intake to 1500-2000cc per day

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | F. Nephrostomy tubes--catheters placed directly into the kidneys<br>1. Seen in patients whose ureters are obstructed and other urinary diversions could not be done<br>2. It is reserved as the last method for urinary diversion<br>3. Complications:<br>a. There is an increased risk of infection in the kidneys<br>b. Maintaining patency can cause problems<br>c. There may be urine leakage around the catheter causing skin excoriation<br>d. Accidental dislodgement of the catheter can occur<br>e. Calculi can form<br>4. Patient Care<br>a. Keep the patient's skin clean with an an application of iodophor solution twice daily<br>b. Be sure the tube is taped securely to prevent accidental dislodgment<br>c. Tape both tubes in a manner so the patient does not lie on them<br>d. Monitor the intake and output and check for the patency of each tube. Notify the physician if a tube becomes occluded<br>e. Periodic changes of the catheters will lower the risk of infection |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | VII. Drug Influence<br>A. Treatment of urinary infection with appropriate antibiotics and sulfur drugs can eliminate the urgency associated with incontinence (Raz, 1978)<br>1. Obtain a urine culture to determine the drug of choice<br>B. Drugs which control involuntary contractions of the bladder (Raz, 1978)<br>1. These are very useful to control dribbling between catheterization<br>2. Instruct patient to void if able prior to receiving the drug<br>3. Some examples: Propantheline Bromide, Imipramine, and Oxybutine<br>C. Drugs which stimulate bladder contractions to reduce high residual of urine in the bladder (Raz, 1978)<br>1. Some examples: Bethanedol chloride, Phenoxybenzamine, and Guanethidine<br>D. Drugs to decrease the symptoms of pain, urgency, and burning from urinary tract infection<br>1. An example: Phenazopyridine HCL |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

SECTION E: PROBLEMS RELATED TO/RESULTING FROM IMMOBILITY

I. Edema

A. Definition of terms

1. Edema - excessive fluid accumulation in cells, tissue or serious cavities

2. Interstitial compartment - in relation to the human body, it is the space between the cells

3. Pitting - to leave an indentation on the skin after applying pressure

B. Edema can be caused by several conditions, all causing a leakage of the fluid from the cells into the surrounding compartments

1. Inflammation can cause edema because of the vasodilator response that the body has to an inflammatory process

2. Obstruction of the lymphatic system causing decreased return of protein to the circulation causing an increase of the oncotic pressure in the interstitial space

3. Congestive heart failure causes an increase in venous pressure which, in turn, causes an increase in the intracapillary hydrostatic pressure

4. Aging causes decreased tissue elasticity and therefore diminished tissue turgor to help facilitate return

5. External compression of the vessels causing decreased return bloodflow and resulting in edema

6. Allergic reactions to food, medications, or external stimuli such as dust or pollen

C. Physical assessment

1. Inspect for swelling of the entire involved body part - measure the circumference of the affected part vs. the normal part for baseline purposes

2. Palpate pulses

3. Palpate for edema by pressing firmly over the bony prominences. Apply pressure for 5 to 10 seconds. Remove the pressure and observe for any pitting

4. If edema is present observe for any external pressures

5. Inspect for any unusual rash

D. Preventative interventions

1. Identify those patients at risk of developing edema, especially those patients who have:

   a. Congestive heart failure

   b. Renal insufficiency

   c. Hypoproteinemia

   d. Starvation (↓serum albumin)

   e. Hepatic disease

   f. Hypernatremia

   g. Obstruction of the great veins

   h. Chronic hypokalemia

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

2. Maintain accurate intake and output records on all patients at risk for developing edema
3. Monitor daily weights, as a patient can gain 10 pounds in water before edema will appear
4. Limit sodium intake for patients at risk
5. Limit fluid intake
6. Make frequent change of positions, avoiding prolonged dependency of extremities - mobilize patients

E. Nursing interventions

- General observation is most important
    1. Maintain accurate intake and output records
    2. Monitor daily weights at the same time each day using the same scale
    3. Limit fluid and sodium intake
    4. Change position frequently to avoid
        a. Dependency of extremities
        b. Skin breakdown - edematous tissue is poorly nourished and breakdown occurs quickly
    5. Skin over pressure areas should be examined and massaged gently with non-alcohol based lotion to stimulate circulation. Techniques reputed to toughen skin usually produce dryness with increased risk of breakdown

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | 6. Position the patient so that the excess fluid will drain away from the affected body part<br>a. Elevate the extremity<br>b. Pulmonary edema - position the patient in the semi-recumbent position to decrease venous return to the heart and lungs<br>7. Jobst, TED stockings<br>8. Administration of Diuretics |

HANDOUT

## ACTION OF DIURETICS

| DRUG | ACTION | OBSERVATIONS |
|---|---|---|
| Acetazolamide (Diamox®) | $Na^+$ and $HCO_3$ not reabsorbed due to carbonic anyhdrase inhibition | Effectiveness if used daily. I & O. Paresthesias and drowsiness common. Hyperglycemia in diabetics. Hypokalemia (Muscle weakness, respiratory difficulty, cardiac irregularities) and metabolic acedoses. (malaise, headache, weakness, nausea & vomiting, abdominal pain, hypernea). |
| Chlorothiazide (Diuril®)<br>Derivatives: Benzthiazide, Chlorthalidone (Hygroton®)<br>Cyclothiazide (Anhydron®)<br>Hydrofluemethiazide<br>Methyclothiazide | Interferes with tubular reabsorption of $Na^+$ | GI irritation. I & O. Weigh gd. Hypokalemia. Hyperglycemia. Hyperuricemia. Orthostatic hypotension. Related to sulfonamides - cross hypersensitivity. |
| Ethacrynic Acid | Blocking of enzyme catalyst reducing $Na^+$ reabsorption. | Ototoxicity. Thromboemobili. I & O. Electrolyte imbalances. GI irritation. Monitor cardiac status, Rebound hypoglycemia on termination. |
| Furosemide (Lasix®) | As with Ethacrynic Acid. | I & O. Ototoxicity. Hyperglycemia. Govt. Electrolyte imbalances. |
| Mannitol | Inhibits tubular reabsorption by increasing osmotic pressure of filtrate. | I & O. Electrolyte imbalances. |

| DRUG | ACTION | OBSERVATIONS |
|---|---|---|
| Mercaptomerin (Thiomerin®) | In acid filtrate, mercury ions decrease reabsorption of $NA^+$ + $H_2O$ in renal tubules | Hypersensitivity reactions. I & O. Electrolyte imbalances. Possible hyperglycemia. |
| Aldactone | Aldosterone antagnoist $NA^+$, $CL^-$, $H_2O$ excretion without loss of $K^+$. | Delayed effect of 2-3 days. I & O. Hypotension. Worsening of impaired liver function. Gynecomastia. |
| Theobromine | Xanthine derivative. Increases renal blood flow. | Gastric irritation. I & O. Vertigo. CNS & Cardiovascular stimulation. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

II. Thrombophlebitis

A. Definition of terms

1. Phlebitis - inflammation of a vein

2. Thrombus - clot found either in a blood vessel or a cavity in the heart

3. Thrombophlebitis - inflammation of a vein, most commonly noted in the lower extremities with the formation of a clot

4. Pulmonary embolism - an obstruction of the pulmonary artery usually caused by a clot originating in the lower extremities

5. Anti-coagulant therapy - drugs that are administered intravenously, intramuscularly or orally to increase clotting time, therefore making it more difficult for clot formation

B. Thrombophlebitis can be caused by hypercoagulability of blood, alterations in the structure of vessels and venous stasis

1. Hypercoagulability of blood - the exact etiology of this phenomenon is not clear. Certain conditions such as myocardial infarction, sickle cell anemia, fever, post-operative situations and oral contraceptives in some individuals is a tendency for development of these problems

2. Alterations in the structure of the vessels - this may result from direct trauma to the vessel as in venipuncture, from certain degenerative diseases such as altherosclerosis and diabetes, and following administration of various drugs (such as antineoplastic chemotherapy). Varicose veins because of the enlarged and tortuous vessel may predispose patient to thrombophlebitis

3. Venous stasis - this may be caused by immobilization because of decreased

TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE

muscle tone failing to help blood return. Prolonged pressure on the vessels (e.g., the tourniquet used in many orthopedic operative procedures), causes blood to stay in the vessels and can encourage clot formation.

4. Metabolities of tumors

C. Assessment

1. History

a. Present illness - discuss the current problem and chief complaint. The patient should be allowed to use own words to describe the type, character and duration of the present symptoms

b. Past medical history - the patient should be questioned regarding other similiar episodes in his/her life. Discuss general health, past illnesses or surgeries and current medications.

c. Social history - identify the patient's activity level including recreational activities

d. Review of systems - complete review of symptoms should be elicited focusing of the respiratory, cardiovascular, and lower extremity musculoskeletal systems. Specifically ask the patient if she/he has noted

- Swelling or pain of the involved limb
- Discoloration of the limb
- Temperature change of the limb

- Chest pain or shortness of breath

2. Physical assessment of the patient with a suspected thrombophlebitis

    a. Examination of involved limb

    - Inspect extremity for swelling, discoloration or change in venous pattern
    - Check for difference in skin temperature
    - Palpate pulses
    - Palpate for edema
    - Palpate for tenderness, increased firmness or tension
    - Gently palpate the path of the vein for tenderness or firm cord
    - Palpate the regional lymph nodes for swelling or tenderness
    - Leg-dorsiflex the foot. If the patient complains of increased pain in the calf this is a positive Homan's sign.

    b. Examination of the chest and lungs is indicated if the patient had positive limb findings or if the limb findings are negative, but the patient complains of shortness of breath or chest pain

    c. Diagnostic tests used to confirm the diagnosis of thrombophlebitis or pulmonary embolism

    - Fibrinogen scan
    - Doppler
    - Chest x-ray

- Lung scan
- Venography
- Phlebography

3. Preventative interventions

   a. Encourage early ambulation for patients who are able to do so

   b. Exercise the lower extremities:

      - Actively by patient every 15 minutes while awake - encourage patient to bend knees and pump ankles
      - Passively - range of motion of lower extremities should be performed by health care provider every four hours or while changing the position of the patient every two hours

   c. Encourage deep breathing exercises that increases venous return

   d. Wrap lower extremities with ace wraps or use elastic stockings

      - Wrap consistently and snuggly - do not wrap tightly
      - Wrap from the bottom of the foot upward
      - Do not allow ace wraps of elastic stockings to bunch or cause increased pressure at the back of the knee
      - Wraps or stockings should be removed every shift to check skin and assure proper support

   e. Elevate the feet approximately $15^{\circ}$ using pillows - be sure not to cause pressure behind the knees

   f. Prevent compression of deep veins with flexion of lower extremities

4. Appropriate therapy to prevent pulmonary embolism

   a. Bedrest is necessary to prevent embolization of the thrombus

   b. Warm moist heat should be applied to the involved limb to help reduce discomfort and swelling

      - Warm compresses

      - Wrap limb in plastic

   c. Anticoagulants administered to inhibit clot formation and extension

   d. Prevention of straining as in Valsalva maneuver; avoidance of quick movements of the involved limb; avoidance of increased intrathoracic pressure e.g., IPPB, holding breath

   e. Diversional activities such as reading or crafts to prevent restlessness

5. Special attention should be given to the patient on anticoagulant therapy to avoid possible bleeding

   a. Clotting time should be monitored daily until the patient is sufficiently controlled on oral therapy

   b. Instruct the patient and family on the need for accurate ingestion of medications

   c. Protect patient from potentially harmful situations such as shaving with a razor blade, walking without shoes or preparing foods with knife blades

d. Instruct the patient and family on safety measures such as handrails on bathtubs

e. Instruct the patient and family on the need for immediate application of pressure to the bleeding site and, if uncontrollable, quick expedition to the local emergency service

f. Instruct the patient and family on the need to carry identification of bleeding disorder

III. Decubiti

A. Pressure sores

1. Pathogenesis: pressure over boney prominence exceeds capillary blood pressure causing tissue ischemia and results in tissue acidosis with increased capillary permeability and edema, vascular thrombosis and eventually tissue necrosis

2. Pressure damage occurs more easily when other factors coexist which reduce the viability/health of body tissues involved. These contributing factors include: anemia, hypoproteinemia, poor hygiene, poor circulation, lymphatic obstruction, sheer force applied to tissue (e.g., by pulling across the bed), loss of muscle tone and muscle atrophy

3. Stages of pressure sore development

a. Hypermia - redness of skin observable within 30 minutes after pressure applied; will disappear within one hour after pressure relieved

b. Ischemia - occurs with continuous pressure of 2-6 hours. Redness

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | takes 36 or more hours to disappear after pressure is relieved.<br>c. Necrosis - begins after six hours of pressure. Blueness or lump observeable<br>d. Ulceration - may involve muscles and bone as well as soft tissue<br>4. Factors which prolong period needed to produce healing of pressure sore include: poor health of tissues in general, protein deficiency, intense inflammatory response, infection, extensive ulceration, hypothermia, extensive scab formation<br>5. Management<br>a. Prevention:<br>● Relief of pressure q 2 h at least (as little as 5 minutes can have benefit) has been shown to be of paramount importance<br>● Inspection of potential areas of pressure (b.i.d.)<br>● Ischemic areas require relief of pressure for 1-3 days<br>● Avoid maceration from incontinence and drainage<br>● Avoid sheer stress from dragging across linens<br>● Good nutrition<br>b. Treatment |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Culture and sensitivity - treat infection with sensitive antibiotics topically (may get systemic side effects in large wound due to absorption)
- Multiple approaches to debridement, and stimulation of healing (See Handouts)

IV. Pathologic fractures

A. Pathologic fractures may be caused by a weakness in the bone secondary to inflammatory disorders, tumor, congential disorders, metabolic bone disease or avascular necrosis of the bone; may be impossible to prevent

1. Inflammation may be present from a direct wound to the area, hematogenous spread of the infection that ends up in a particular bone
2. Tumors that are both benign and malignant may cause pathologic fractures
3. Metabolic bone disease (primary or secondary to paraneoplasm syndrome such as rickets, osteoporosis, and hyperparathyroidism) may cause fractures
4. Avascular necrosis either from trauma or radiation makes the bone weaker secondary to the loss of blood supply and death of the bone

B. Pathological fractures will usually heal if the rate of bone formation excedes the rate of bone resorption. Fractures secondary to an inflammatory process generally require the concurrent use of antibiotics for control of the infection. The pathologic fracture through an area of tumor generally requires internal fixation with concurrent radiation or chemotherapy and in most cases it will reunite

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

C. Preventative interventions

1. Identify those patients at risk for pathologic fractures
2. Limit strenuous activity because the slightest trauma can cause a fracture in these patients even during normal daily activities
3. Provide safety measures such as handrails near showers or safety grips on the bottom of the bathrub; removal of throw rugs; use of low heeled, non-slip shoes
4. Completely support all extremities of the patient at risk during repositioning in bed. During ambulation activities support the patient and guard against falls. Discourage hurried activity.

D. Management of the patient with a pathologic fracture requires that constant attention be paid to unaffected limbs in one's haste to care for the affected body part

1. Maintain alignment of fracture site by cast, traction, pillow splints, and appropriate positioning
2. Protect the patient from reinjury - primary goal
3. Avoid quick or violent movements that might cause a new fracture
4. Provide comfort measures for this patient who will be immobilized for a long period of time
5. Frequently reassess status of other bones; pain and edema

# METHODS USED TO RELIEVE PRESSURE TO PREVENT PRESSURE SORES

| METHOD | COMMENTS |
|---|---|
| Gel pads | Act as artificial fat over boney prominences dispersing pressure over large area |
| Sheepskin | Use against bare skin; and ↓friction, absorb moisture, reusable |
| Circoelectric bed | Stryker or Foster frame - to aid turning; use sheepskin pads also; cumbersome and time consuming |
| Alternating pressure mattress | Use of pillows, pads, etc., negate effect; annoying motor noise; must check operation often |
| Air mattress | Bulkiness impedes care; use of Sears camping mattress as good as medical type and less expensive and not as much disorientation |
| Water bed or mattress | distributes pressure over all body; water beds can lead to disorientation; filling Sears best camping mattress with warm water is inexpensive alternative |
| Glass sphere bed | Patient rests on bed of glass spheres supported by air; pressure exerted on body is less than capillary blood pressure so no ischemia develops; experimental and very expensive - hundreds of thousands of dollars and not shown to be more effective than every two hour turning. |

| METHODS | RATIONALE | ADVANTAGES | DISADVANTAGES |
|---|---|---|---|
| Collagenase | Digest collagen in necrotic wound debris | Debridement complete in 10 days Epithelization evident in two weeks. Pre-treatment with sutilains enhances effect in deep lesions | Irritates normal tissue |
| Mercurochrome (10% in packing) | Antiseptic stimulate granulation | Use after debridement | Doesn't work at all on some people |
| Karaya powder | -- | Successful reports when everything else has failed | Rings may extend pressure to fragile areas at margins |
| Gelfoam powder | Hastens granulation | Airtight dressing changed only q3-7 days. Wound cleansed only if contaminated | -- |
| Heat lamp, and/or massage, hydrotherapy | vasodilation and debridement | Readily available | Danger of too much |
| Sugar | Stimulate granulation 10pH→ vasodilation | Also used in paste form for packing of ulcer for debridement | -- |
| Topical Insulin | -- | Study showed benefit over light cradle | -- |
| Electrotherapy | Probably vasodilation | See Pain - Use of TENS | -- |
| Carbon dioxide laser | Debridement | Provides hemostasis | Limited availability extensively trained operator |
| Hyperbaric oxygen 6-8 hours/day | ↓bacterial growth | ↓healing time | -- |

## METHODS USED TO TREAT PRESSURE SORES

| METHOD | RATIONALE | ADVANTAGES | DISADVANTAGES |
|---|---|---|---|
| Continuous acetic acid drip<br>Irrigation to sore (0.5-1% solution) | Alter media for growth of infectious organism | ↓Pseudomonas | Proteus and staph |
| Sodium oxychlorosene; irrigation or wet dressings tid (0.4-0.5%) | Alter media | ↓gram - and pos organisms fungi yeast and viruseo | Must be mixed frequently q8h |
| Surgical Debridement | Eliminates culture for growth of infectious organism: ↑granulation | Fastest way to prepare area for healing | May produce inadequate bed for graft; may need to also use enzyme to complete debridement |
| TCN (Trypsin-Chymotrypsin-Neomycin) | Enzymatic debridement | -- | Antibiotic exposure may lead to secondary infection |
| Fibrinolysin - Desoxyribonuclease (FD) | Enzymatic debridement | Same use | Inadequate in deep or large sores because acts slowly |
| Stretokinase - Streptodornase (SK-SD) | Fibrinolytic enzyme<br>Liquifies exudate making aspiration possible | Acts only on nucleoprotein of dead cells. Installation of SK-SD beneath skin flap may prevent slough due to fluid accumulation under flap | -- |
| Sutilains | Proteolytic enzymes<br>Digests necrotic tissue | 5-16 more active than other enzymes; normally non-toxic; can have area ready for granulation in 3-14 days | Very deep sores still require surgical debridement as well; some people don't respond to this agent |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | PROCESS FOR DISCUSSION<br>A 64 year old lady was brought to the emergency room by her son. She began complaining of pain in her right hip after she stepped off a curb. She did not fall. Past medical history is significant for a mastectomy for cancer six years previously. On physical examination the woman is found to be in significant pain with her right leg internally rotated and shortened. Discuss appropriate interventions at this time and differential diagnosis.<br>Diagnosis: 64 year old female with pathologic fracture of the right hip secondary to breast cancer metastasis.<br>Note:<br>Refer to: Exercises for Expediting Mobility (and Decreasing Disability) in Bedridden Patients. Jungreis, S.W. Nursing 77, August, 1977, p. 47-51. |

G. SECTION F: INFECTION AND FEVER

I. Infection can be described as the implantation and successful replication of a micro-organism on or in the tissue of a host.

  A. Three elements are required for infection to be spread:

    1. A source of infecting organisms

    2. A means of transmission for the organism

    3. A susceptible host

      - The source of infection refers to the site from which the organism passes immediately to a host

        - Examples: contaimnated instruments used to treat and diagnose, people with active infections or carriers of the disease

        - Types of carriers:

          -- incubation phase, i.e., chicken pox

          -- convalescent carrier, i.e., hepatitis B

          -- chronic carrier, i.e., staphylococci

          -- mechanical carrier, i.e., fecal contamination of the fingers with the Salmonella organism

    4. Cancer patients and institutionalized patients are highly susceptible to infections

  B. Transmission of infection:

    1. Contact transmission - contact between a susceptible host and the source, with

the subsequent transfer of the infecting agent.

a. Direct contact: direct physical transfer to a susceptible host by an infected person; example--nurse giving patient a bath

b. Indirect contact: contact of the susceptible host with contaminated inanimate articles; example--use of common bar of soap

c. Droplet spread: considered contact since the organisms travel only a few feet between the source and susceptible host; example - streptococcal disease

2. Vehicle Transmission: common route of transmission from a single source into contact with a susceptible host; example-hepatitis from contaminated blood.

3. Airborne Transmission: via droplet nuclei or reaerosolized dust.

a. Droplet nuclei - tiny particles that are capable of remaining airborne for long periods of time and of traveling great distances before coming into contact with the susceptible host; example - Histoplasmosis, tuberculosis

b. Reaerosolized dust - some organisms settle and mix with dust, remaining viable and are reaersolized through agitation of the dust.

4. Vector Transmission: insect carrier; example - Rocky Mountain Spotted Fever.

C. Susceptible Host

1. Normal defenses:

a. Skin and mucous membrane

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Dry, mildly acid, frequent turnover of cells causes shredding of bacteria from surface, antibodies and lysozymes secreted in mucus, tears

b. Respiratory tract

- Antimicrobial substances (lysozymes, antibodies)
- Aerodynamic expulsion (sneeze, cough, etc.)
- 90% of deposited material is removed in one hour

c. GI tract

- Enzymes, peristalsis and normal flora

d. Genito-urinary tract

- Ph, voiding often

e. Health immune response

2. Predisposing factors

a. Damage to barrier: surgery, stomatitis, venipuncture, suctioning, catheter

b. Obstruction: tumor growth, edema

c. Impaired response: loss of gag reflex, bladder dysfunction

d. Immune deficiency

- By virtue of fact person has cancer
- Humoral deficiency in myeloma, CLL, lymphosarcoma
- Cellular deficiency due to chemotherapy, steroids, certain cancers

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | ● Neutrophil deficiency due to chemotherapy, steroids, antibiotics, marrow involvement<br>3. Common Infections - should identify organism before treating, i.e., always obtain culture and sensitivity<br>a. Staphylococcus aureus<br>● Factors involved: injury to barrier, immunity, obstruction<br>● 70% nurses are carriers - keep patient out of institutions<br>● Sites:<br>- Skin: impetigo, boils, carbuncles<br>- Pneumonia: dry cough, malaise, fever, chills, cyanosis<br>- Endocarditis: fever, chills, anorexia, petechia, 40% have meningitis also, 10-40% palpable spleen<br>- Septicemia - 50% are hospital acquired<br>- Osteomyelitis - low grade fever, local pain, swelling, redness, x-ray not diagnostic<br>● Prevention: handwashing, pulmonary hygiene, separate high risk patients<br>- Good handwashing procedures only thing that really decreases infection<br>● Treatment<br>- Drain abscess<br>- Antibiotics based on C & S |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | b. Streptococcus pyogenes<br>● Factors involved: injury to barrier, immunity, crowded conditions, airborne, dental extraction<br>● Sites<br>- Pharyngitis: abrupt sore throat, malaise, fever, redness, lymphoid hyperplasia, hoarseness, cough<br>- Otitis media, sinusitis and meningitis secondary to Pharyngitis<br>- Treatment for Pharyngitis and Otitis media<br>-- antibiotics based on C & S<br>-- 25% of family are carriers<br>- Acute Glomerulonephritis<br>-- abrupt onset proteinuria, hematuria, edema, ↑BP, dull back pain, ↑sedrate, ↑BUN and creatinine<br>-- treatment includes bed rest, salt and fluid restriction, diuretics, treat hypertension, antibiotics based on C & S and treat infected family members<br>c. Pseudomonas aeruginosa (Gm negative bacillus)<br>● Source: earth, water, food, fruit, plants, feces, hand to hand, 22% hospital acquired<br>● Host factors: ↓Immunity, leukopenia. indwelling line, respiratory therapy, use of broad spectrum antibiotics |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Common sites
  - Respiratory: early congestion, pulmonary edema, empyema, chills, fever, gray coloring, chest pain, dyspnea
  - Treatment: Gentamycin, carbenicillin, polymycin, tobramycin based on C & S
  - Urinary Tract
    - -- burning, frequency, odor, cloudy
    - -- treat with Gentamycin based on C & S
  - Osteomyelitis
  - CNS
    - -- most of them secondary
    - -- treat: drain abscess, treat with combination of antibiotics
  - Wound infection
  - Skin infection
- Vaccine provides protection after 5-7 days lasts 2-5 months
  - Used in leukemias
  - Local reactions, fever, malaise

II. Candidiasis - fungal infection

A. Local candida: confined to superficial surfaces: e.g., skin, hair, nails, mouth, vagina, conjunctiva

1. Incidence of candida in oral flora of

normal population approximately 40-60%

2. Patients with head and neck tumors, treated with radiation therapy have a more acid pH and an increased incidence of candida infections

B. Systemic Candida: considered disseminated if there is invasion of the esophagus or further down the gastrointestinal tract; also when there is organ invasion

1. Clinical predispositions: myeloproliferative and solid organ tumors, immunosuppressed transplant recipients, post operative patients

2. Invasion of specific sites by Candida

   a. Oral Candida: may be difficult to distinguish from stomatitis. Increased risk if neutropenic and/or taking steroids

3. Treatment of oral Candida

   a. Mycostatin suspension one million units (10") to swish and swallow q 4° in conjunction with Mycostatin Lozenge, one to suck on q 4°. Prophylactic therapy with Mycostatin has been found to be ineffective

   b. Miconazole 500 mg po qid has been found to protect patients from colonization with Candida

   c. Clotrimazole lozenge 50 mg five times each day is the therapeutic dose; no side effects

4. Gastrointestinal Candidiasis - symptoms: fever, occasionally diarrhea; in esophagitis--pain substernal referred under angles of mandibles and dysphagia

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

   a. There can be direct seeding of Candida from the GI tract to the portal vein leading to widespread dissemination

   b. Treatment: Mycostatin 10 million (100cc) swish and swallow q 2° or low dose systemic therapy antifungal agent

5. Candida pneumonia: Enters the lung via aspiration, hematogenous spread or aerosolization

   a. Symptoms: often absent; also sputum specimens may be contaminated by oral secretions; so only reliable method of diagnosis is lung biopsy

   b. Candida pneumonia associated with hemorrhage in the pleural cavity, clinical aspiration pneumonitis

6. Renal Abscess: invasion by hematogenous spread

   a. Signs and symptoms: mild azotemia and fever

   b. Diagnosis difficult. Colonized lesions may be so small that they may be missed when biopsied

7. Bladder: incidence increased in patients with indwelling catheters who have diabetes mellitus and are on therapy with antibiotics

   a. Usually asymptomatic

   b. Urine C & S can only be used as a diagnostic test if obtained via straight catheterization

   c. Treatment: may resolve simply be removing the catheter, however, bladder irrigation with a dilute antifungal solution is also employed

8. Fungus ball of kidney: invasion and subsequent sloughing of renal papillae leading to tangled masses which can obstruct the ureters

   a. Diagnostic test is an IVP which will show sloughing

   b. Symptoms: pain and a decrease in urinary output

   c. Treatment: the fungus ball may break up spontaneously, or it may require surgical removal

9. Candidemia: may or may not be significant

   a. Blood specimens may be contaminated by skin lesions or Candida colonies at the tip of plastic intravenous catheters

   b. Treatment: in the non-immunosuppressed patient, treatment may not be required once the catheter is removed. Therapy with a systemic antifungal agent is advised when the patient is immunosuppressed, receiving broad spectrum antibiotics and remains febrile and displays one or more of the following symptoms:

      - Isolation of Candida from 2 or more sites

      - Increased urinary colonization

      - Esophagitis

      - Skin or ocular lesions

C. Systemic therapy for fungal infection

   1. Miconazole: broad spectrum of activity including fungi and gram positive bacteria,

therapy usually needed for 2-3 months

2. Flucytosine: related to 5-flurouracil. Narrow spectrum antifungal agent. High incidence of development of resistance

   a. Dosage: 150-200 mg/kg/day in 4 divided doses

   b. Side effects: bone marrow depression

3. Amphotericin B: high activity against many species of fungi; ineffective against bacteria, viruses

   a. Dosage: 1 mg/kg/day infused over 4-6 hours. Initial dose is 1 mg and subsequent dosages are titrated up to lessen the chance of a hypersensitivity reaction

   b. Daily dosage greater than 50 mg should be mixed in 1000 cc $D_5W$

   c. Other additives should be avoided, however, Heparin 100 and Hydrocortisone 100 mg are often placed in the solution to decrease the incidence of local thrombophlebitis and shaking chills, respectively

   d. Side effects

      - Renal toxicity: dose related and reversible

        - Mannitol prior to and after Amphotericin may decrease toxicity

        - Administration of Gentamycin worsens renal toxicity

      - Monitor: intake and output, creatinine levels, BUN

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Hypokalemia: result of potassium leakage from red blood cells
  - If there is a sudden increase in potassium in the urine the drug should be discontinued
  - Monitor: Potassium urinary levels
- Hematopoietic toxicity: commonly manifested as anemia
  - Monitor: blood counts (WBC, RBC, PH.)
- Chills, fever, nausea: exogenous pyrogen
  - Premedication with Benadryl and/or hydrocortisone
  - Combinations of Thorazine, Demerol, Phenergan or aspirin are also helpful to reset the hypothalamus set point to a lower level
  - Administration of Amphoteucin along with flucytosine has a helpful synergistic action

III. Pneumocystis Carinii: protozoan

A. Presents as rapidly progressing diffuse interstitial pneumonia

B. Observed in four clinical settings:

1. Malnourished or premature infants
2. Children with primary immunologic deficiency disorders
3. Patients with acquired immunologic disease

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

4. Patients receiving immunosuppressive therapy

C. The peak onset of pneumocystitis carinii pneumonia can be related to the cessation or tapering of corticosteroids 5 days to 3 weeks prior to the development of clinical symptomatology.

D. There is evidence of the presence of subclinical pneumocystis carinii early in life. Approximately two-thirds of normal children have acquired humoral immunity to the organism by the age of 4 years.

E. The rebound pneumonia which is seen when steroids are discontinued appears to be the result of the slow proliferation of the organism to clinically significant quantities which when the immunosuppressive agent is withdrawn allows that host to mount an inflammatory attack leading to clinical pneumonia

F. Transmission suspected via the respiratory tract

   1. Incubation period: undefined

G. Respiratory isolation of the infected person to decrease the risk of producing a carrier of the parasite.

H. Constellation of clinical symptoms:

   1. Progressive dyspnea

   2. Fever to 40°C

   3. Nonproductive, dry cough

   4. Chest pain and night sweats

   5. Cyanosis

6. Chest x-ray findings are variable and range from completely normal to severe bilateral interstitial infiltrates involving all five lobes of the lung

I. Diagnosis: Vigorous attempts to procure a specimen via nasotracheal suction should be made to spare the patient undergoing anesthesia and an operative procedure to identify the cyst.

1. Fluid obtained by transthoracic percutaneous needle aspiration of the lung parenchyma will contain Pneumocystis carinii cysts with approximately 85% accuracy in the first specimen and with 95% accuracy in the second specimen. Since Pneumocystis carinii pneumonia is rapidly fatal if untreated, open lung biopsy is both justified and considered to be the diagnostic procedure of choice

J. Treatment

1. Pentamidine Isethianate: action basically unknown

    a. With early diagnosis and treatment, curative in approximately 75% of cases

    b. Not commercially available in the United States; must be obtained from the Center for Disease Control, Atlanta, Georgia

    c. Dose: 4 mg/kg IM qd x 10-14 days; may be given IV very slowly, however side effects greatly increased. Intramuscular injection should be administered via Z-tract technique to palliate accompanying painful erythema and prevent leakage of the medication into subcutaneous tissue

d. Immediate systemic side effects include facial sweating, hypotension, headache, nausea and vomiting

- It is recommended that vital signs be taken immediately prior to administration and then every 20 minutes for the following two hours
- Some institutions require that a physician be present when the injection is given and that an emergency cart is in close proximity to patient's room

e. Delayed systemic side effects include hypocalcemia, hypoglycemia, azotemia, nephrotoxicity (50%), folic acid deficiency

- Therefore, monitor intake and output, BUN and Creatinine levels
- Also, observe patient for signs and symptoms of hypocalemia and hypoglycemia

f. Folate 1 mg po qd is often administered concurrently with Pentamidine Isethionate

2. Trimethoprim - Sulfer methoxazole (Septra-Bactrim)

a. This agent has been used extensively in Europe for the treatment of bacterial infection

b. Eight years ago, it bacame commercially available in the U.S.A. and was indicated for use in the treatment of chronic urinary tract infection

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | c. Broad spectrum of activity against both Gram positive and negative organisms |
| | • Exceptions are Pseudomonas aeruginosa and Bacteroides fragilis |
| | - against Pneumocystis carinii cure rate of 77% (at St. Judes) |
| | d. Dose: 20 mg/kg/day divided into three doses every eight hours, there is a 1:5 ratio of Trimethoprim to Sulfamethoxazole, i.e., 80 mg:400 mg. |
| | • The drug may be administered intravenously or by mouth |
| | • The pattern and relative incidence of adverse reactions are those expected from a sulfonamide of low toxicity |
| | • Therefore, this drug is not administered to patients with known sulfa sensitivity |
| | e. Folic acid deficiency is associated with use of Trimethopraim--Sulfamethoxazole and supplements are commonly administered concurrently |
| | f. Although not documented, oral candidiasis appears to be more prevalent in patients receiving therapeutic dosage |
| | • Prophylactic doses of this drug have been given to patients at risk of developing Pneumocystic carinii pneumonia with good effect (preliminary results) |
| | g. Advantages of Trimethoprim-Sulfamethoxazole over Pentamidine Isethionate: |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Minimal adverse effects
- Oral administration
- Commercially available
- Prophylaxis
- No recurrances documented

NOTE TO INSTRUCTOR: DISCUSSION QUESTION

The following questions should be discussed by the group following item 2g.

Discussion Question

When terminally ill individuals develop an infection should they be treated? Aggressively? With antibiotics? Or should one let nature take its course?

Discussion Points

- Institutional procedures used to treat infections; what are the side effects; do we want these
- Cost
- Is there really going to be a benefit to patient

IV. Genreal Nursing Interventions

A. Nursing measures

1. Good, regular handwashing
2. Promote general good hygiene
3. Separate at risk patients
4. Diligence in obtaining accurate cultures
5. Blood cultures need to be drawn three times

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | 6. Culture foci of infecting organism: disinfectant, soap, sinks, food, patients flowers/plants, IV fluids, equipment<br>7. Change IV tubing q 12-24 hours<br>8. Maintain sterility and lubricate all tubes entering body orifices<br>9. Frequently change dressings; use ostomy/fistula bag if large amount of drainage<br>10. Treat patients symptoms aggressively<br>11. Get patient out of hospital as quickly as possible |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

V. Temperature Regulation.

The hypothalamus is the body's center for thermoregulation. It acts as a thermostat with set-point (i.e., 37°C).

A. Peripheral Thermoreceptors: located in the skin and sense warm and less warm temperatures (not cold). This information is transmitted to the hypothalamus via afferent nerves and ascending pathways.

The body's response to this information is to either:

1. Vasoconstrict skin vessels and shiver, thereby retaining or producing heat; also curl up and reduce surface area

2. Vasodilate skin vessels, sweat, increase surface area by stretching out and decrease muscle tone, resulting in heat loss

B. Central Chemoreceptors: probably located in the hypothalamus itself and other deep body structures.

C. Mechanisms of Fever

1. Hypothalamus thermostat is reset to a higher level

    a. Mechanisms responsible for actual elevation of set-point unclear

    b. Initiation of thermoregulatory responses designed to maintain an elevated body temperature

        - Example: In fever, when the thermostat is raised, the body feels cold and chill often develops. Regulatory mechanism start conserving heat via vasoconstriction of skin vessels, curling up to reduce surface area

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

and shivering. Cerebral cortex sends message to put more clothes on

D. Activators of Fever

1. Exogenous pyrogens: external substances that when introduced into the body cause the hypothalamus to reset thermostat to a higher level

   a. Examples: Gram positive and negative bacteria, viruses, fungi, yeast protozoa

      - Endogenous pyrogens: substances within the body that cause reset of the hypothalamus to a higher level

   b. Examples:

      - Hypersensitivity reaction (antigen-antibody)
        - Response to infectious agent when previously sensitized, i.e., skin testing
        - Drug reaction, i.e., ampicillin, blemycin
        - Allergic reaction to toxins present in food
        - Rejection of transplanted tissue
      - Tumor: fever has been associated with malignancy
        - Production of some toxin by the tumor
        - Tissue necrosis with the release of some pyrogenic material

2. Fever has been implicated as a helpful mechanism in host survival. Several

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

effects have been identified:

a. Direct effect of fever on pathogens--All pathogens have optimal temperature range for reproduction and growth. Elevated body temperature may alter host environment sufficiently to inhibit reproduction and growth of pathogens

b. Activities related to increased reactions at higher temperatures

c. Liberation of lysosomal enzymes--These enzymes breakdown certain substances; i.e., pathogens

d. Increased production of Interferon activated by fever--Interferon is a protein produced in response to intracellular contact with various foreign substances, especially viruses. (Interferon is currently being studied by investigators who hypothesize that some forms of cancer may be initiated by viruses and therefore combated by Interferon)

e. Transformation of lymphocytes enhanced by fever

f. Lymphocytes are specialized white blood cells involved in host cellular and humoral immunity. In response to an activating substance, lymphocytes proliferate and are transformed, thereby enabling them to participate in the immune response

g. Increased mobility of granulocytes--Granulocytes are white blood cells which are involved in the phagocytosis and destruction of pathogens

E. Management of Fever - fever is merely a symptom

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

1. Signs of fever
   - a. Normal oral body temperamture is approximately 36°C-37.5°C (96.5°F-99.5°F)
   - b. Rectal temperature is 0.5°C or 1°F greater than oral temperature
   - c. Axillary temperature is 0.5°C or 1°F less than oral temperature
   - d. The rectum is the most accurate site to determine temperature since there is a good blood supply in this area and it is unaffected by air
2. Contraindications: patients with cardiac disease, rectal or perineal surgery, leukopenia, thrombocytopenia, diarrhea or other rectal disorders. A patient with an ileostomy or a colostomy can have his temperature taken via stoma.
3. The mouth also has good blood supply for the procurement of an accurate temperature, however, many variables affect the reading.

   Example: Ingestion of hot/cold foods, smoking
4. Contraindications: patients who are mouth breathers, postoperative oral surgery, have severe stomatitis, or are combative or comatose.
5. The axillary temperature is the least reliable since the skin is apt to be cooler than the internal temperature due to exposure to air.
6. Along with elevation of temperature, there are other signs of fever which include:
   - a. Flushed face due to vasodilation of skin vessels

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

b. Hot dry skin due to evaporative mechanism

c. Sympathetic nervous system response of rapid pulse caused by increased heart rate and contractility

d. Thirst due to a release of scant, thick saliva

e. Nausea and vomiting due to a decrease in gastrointestinal motility and tone and also a decrease in blood flow to this area

f. Headache and malaise

F. Medical Care of the Patient with Fever

1. The major consideration in the management of fever is determination of its cause. The usual method by which this is done is the procurement of various specimens from the host to ascertain the presence of a pathogen.

2. If a pathogen is suspected as the cause of fever appropriate antibiotic therapy is instituted. Depending upon the severity of the febrile episode, an antipyretic, i.e., aspirin or acetaminophen, may also be given.

3. If the cause of fever is a hypersensitivity reaction, treatment is directed at alleviation of the symptom. Agents which may be employed include:

    a. Antihistamines (Benadryl)

    b. Steroids (Hydocortisone or Prednisone)

    c. Antipyretics

    d. Combinations of Meperidine, Hydrocloride, Chlorlpromazine and Promethazine Hydrochloride as well as aspirin and acetaminophen reduce the set-point of the hypothalamus when it is abnormally high. They do not affect a normal thermostat setting

G. Nursing Care of the Patient With Fever

1. Sponging with tepid water

   a. Sponge areas in a systematic patting way. The patient will lose heat via conduction and evaporation and the patting motion will keep the blood coming to the surface

   b. Avoid using cold water since this will induce shivering and further increase the temperature. Ice packs applied to the axillae, groin, back of knees may be used in very extreme cases

2. Hypothermia Blanket

   a. Cover cooling blanket with a bath blanket for comfort

   b. Cover patient only with a light sheet to allow dissipation of heat

   c. Caution must be exercised to avoid dropping the temperature too quickly. Temperature should be taken every fifteen minutes

   d. Turn patient frequently to allow circulation to return to cooled areas

   e. Turn blanket off when the temperature is within 1°C or 2°F of desired. There will be a subsequent downward drift and further reduction of temperature

H. Related Problems of Fever

1. Dehydration: caused by profuse sweating, accelerated metabolism and loss of water vapor.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | a. Review of dehydration (skin turgor, dry, coated, fissured tongue, sunken eyeballs, decreased urine output, increase in urine specific gravity).<br>2. Chills: administer ASA or thorazine in attempt to reset thermoregulatory center in the brain.<br>I. Interventions<br>1. Carefully monitor intake and output. Include urine, stool and gastric drainage.<br>2. Urine specific gravity<br>3. Replacement of fluids orally or if ordered by physician, intravenously<br>(See also section on nutrition)<br>4. Nutrition: ↑consumption of calories due to increased metabolic rate.<br>5. When febrile episode controlled, encourage diet high in protein and calories (See nutrition) |

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

## SECTION G: Fatigue

I. Fatigue is a subjective evaluation of sensations associated with distress, decrease in motor and mental skills and increased task aversion (Haylock and Hart, p. 461)

- A. Distressing symptom to patient and family which is often not assessed
- B. Not only the amount of fatigue but the meaning of the fatigue to the patient and family that is important
- C. Fatigue is also distressing to staff
- D. Assess using 0-10 scale

II. Causes of Fatigue

- A. Physiologic factors
  - 1. Malnutrition
    - a. Negative nitrogen balance resulting from decreased protein intake
    - b. Ketosis resulting from decreased caloric intake and using fat stores in body for energy
  - 2. Poor cardio-pulmonary reserve
    - a. Metastasis
    - b. Effects of therapy on lungs
    - c. Age
    - d. Chronic illness
    - e. Terminal processes
  - 3. Prolonged mental and/or physical stress

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

4. Side effects of drugs: sedatives, hypnotic tranquilizers, anti-histamines, analgesics, tetracycline, adrenocorticosteroids, ergot, insulin, digitalis

5. Effects of therapy

    a. Anemia from chemotherapy

    b. Accumulation of by-products of cellular destruction from radiation

    - Extra energy required to maintain cell growth in cancer cells
    - Extra energy required for healing after surgery

    c. Anemia

    d. Infection

    - Extra energy required with fever
    - By-products of cell destruction accumulate causing fatigue

    e. Electrolyte disturbances

    - $\downarrow$Na, $\downarrow$ or $\uparrow$ Mg, $\downarrow$K

    f. Renal or hepatic dysfunction

    g. Endocrine disorders

    - Diabetes, alterations in pituitary, adrenal, thyroid or parathyroid function

B. Psychosocial factors include:

1. Depression

    a. Frequently is a reactive state secondary to disease. Anti-depressants are frequently effective

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

b. Diagnostic criteria for major depressive episodes (DSM-III, 1980) 4 criteria need to be present in a patient

- "Dysphoric mood or loss of interest or pleasure in all or almost all usual activities and pastimes. The dysphoric mood is characterized by symptoms such as the following: depressed, sad, blue, hopeless, low, down in the dumps, irritable. The mood disturbance must be prominent and relatively persistent, but not necessarily the most dominant symptom, and does not include momentary shifts from one dysphoric mood to another dysphoric mood, e.g., anxiety to depression to anger, such as are seen in states of acute psychotic turmoil. (For children under six, dysphoric mood may have to be inferred from a persistenly sad facial expression)" (DSM-III, 1980)

c. Diagnosis of depression

- Current classification mandates that at least four of the below listed signs be present daily for a two week period:
  - Change in appetite with weight loss/gain
  - Inability to sleep/constant sleeping
  - Observable motor agitation/retardation (not only subjective report by patient)
  - Disinterest in activities of daily living
  - Feelings of fatigue

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | - Poor self-concept/self-esteem<br>- Patient reports being unable to think clearly or to concentrate<br>- Death wishes which reoccur/attempted suicide<br>● Above symptoms are not associated with schizophrenia, paranoid disorders, organic disorders or a bereavement which is not complicated<br>2. Interventions for patients with depression:<br>a. Activity schedule<br>● Graded increments in activity assigned<br>● Role play, imagery<br>b. Point out alternative thoughts/explanations to repetitive negative thoughts (be realistic, however)<br>c. Reduce overall problem to manageable components and problem solve<br>d. Question validity of hopelessness--almost always something to hope for<br>e. Structure environment to provide maximum pleasure<br>f. Question validity of self-criticisms<br>g. Role play<br>h. Distraction, imagery<br>i. Humor<br>j. Set priorities |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

        k. Review life with emphasis on positive aspects

    3. Chronic anxiety with or without hyperventilation

    4. Situational exhaustion--patient is trying to function beyond abilities

        - Establish priorities

        - Provide care for non-priority aspects

        - Contract with patient and family for schedule that includes patient's priority activities and rest, e.g., it may be more important for a patient to put on her make-up than to feed herself

III. Nursing Management

A. Assessment

B. Set priorities

    1. Do most important things first before patient becomes fatigued

    2. Mobilize resources

    3. Plan periods of rest

C. Set realistic goals

D. Symptom management

    1. Nursing measures regarding fatigue include the following:

        a. Determine cause of fatigue

        b. Determine distress it causes patient, family and staff

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | ● Using 0-10 scale, where 0 = no fatigue, and 10 = maximum tiredness<br>● Also use 0-10 scale, where 0 = it doesn't bother me to be so fatigued to 10 = the fatigue bothers me more than anything<br>● Some patients will report fatigue of 2-3 that is maximally distressing (10); others when maximally fatigued (10) don't care (0-2)<br>c. Determine priorities for patient, family and staff<br>d. Resolve conflicts regarding priorities<br>e. Plan activities/rest to support priorities; provide maximal assistance in areas of low priority so patient can do priority activities<br>● Mobilize resources--including volunteers<br>● Distraction<br>f. Treat depression<br>g. Facilitate relief from other symptoms that deplete energy reserves |

## SECTION H: Dyspnea

I. The normal respiratory rate is 12 to 18 breaths/minute. The ratio of pulse to respiration is 5:1. Count respiratory rate for 30 seconds and multiply by 2. (Counting the respiratory rate for 15 seconds may give a plus or minus of four breaths.)

II. Overview of the Respiratory System

A. Conduction and exchange of gas. (See Figure 1)

1. The airways of the lung consist of a series of branching tubes which become shorter, narrower and more numerous from the trachea to the bronchia. These tubes are referred to as the tracheobronchial tree.

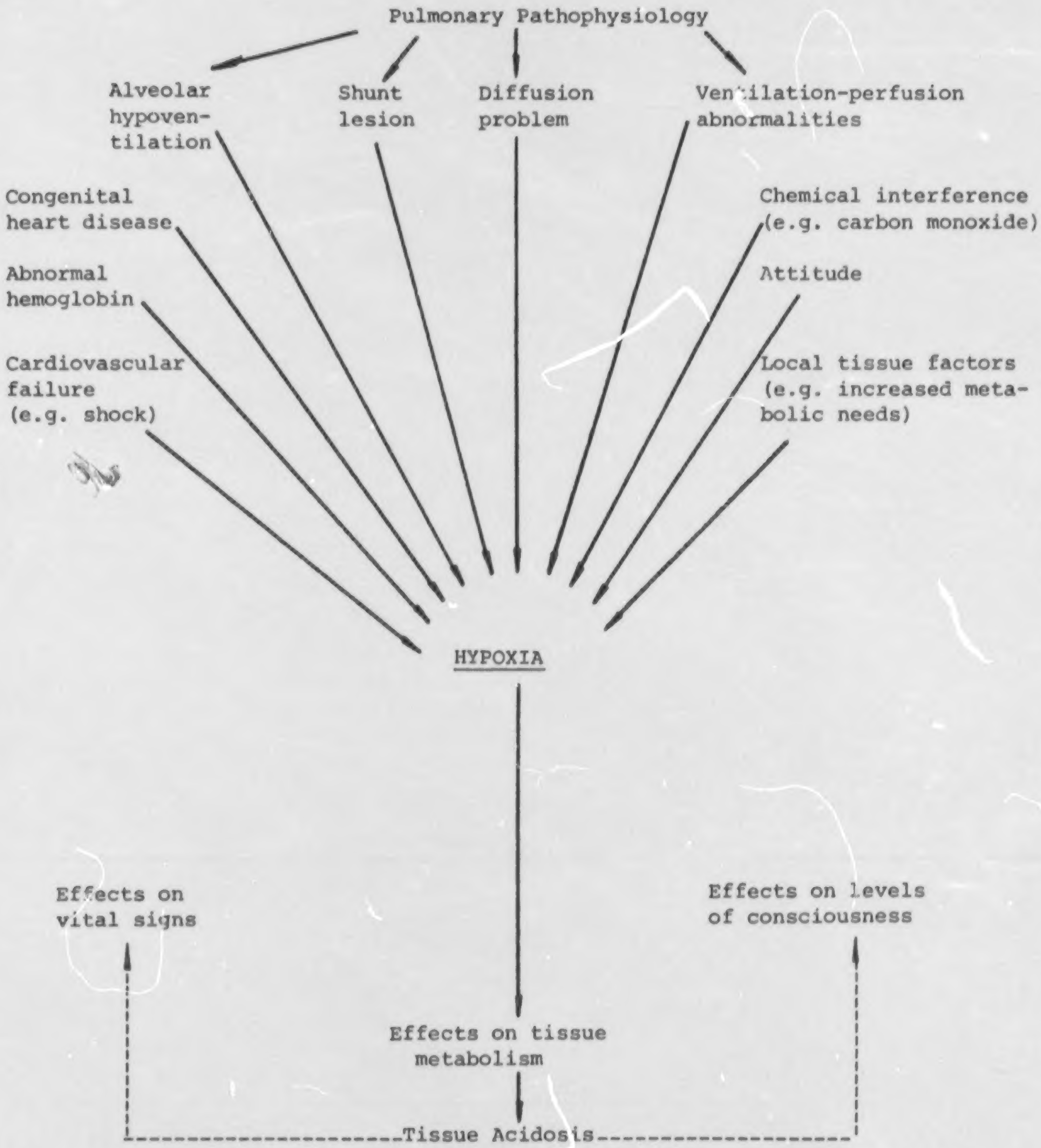
2. The airways are the conducting pathway for gas into and out of the exchange region of the lung. The branching anatomy of the lung gives rise to a large cross sectional area which is ideal for diffusion of gases.

3. Gas travels via diffusion from an area of high pressure to one of low pressure

4. The exchange regions for gas in the lungs are the alveoli and pulmonary capillaries. In these regions gas and blood are in very close proximity. Each pulmonary capillary is wrapped around a large number of alveoli.

5. The lungs work most efficiently when the amount and rate of air reaching the alveoli (ventilation) matches the amount and rate of blood flowing in the capillaries (perfusion)

FIGURE 1. Hypoxia; mechanisms and effect


Pulmonary Pathophysiology
Alveolar hypoventilation
Shunt lesion
Diffusion problem
Ventilation-perfusion abnormalities
Congenital heart disease
Abnormal hemoglobin
Cardiovascular failure (e.g. shock)
Chemical interference (e.g. carbon monoxide)
Attitude
Local tissue factors (e.g. increased metabolic needs)
HYPOXIA
Effects on vital signs
Effects on levels of consciousness
Effects on tissue metabolism
Tissue Acidosis

(Brannin, P.K. "Oxygen Therapy and Measures of Bronchial Hygiene," Nursing Clinics of North America, 9 (1),:111-121, March 1974 (With permission).

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | 6. By respiration is meant the exchange of carbon dioxide and oxygen between the atmosphere and the alveoli, between alveoli and blood, and between blood and the tissues<br>7. In respiratory disease, there is often a mismatch between ventilation and perfusion. The result is an increase in the amount of work required to keep the system functioning<br>B. Thorax and diaphragm<br>1. The thorax or chest cavity plays a major role in respiration<br>2. The contraction and relaxation of the diaphragm-the muscle of respiration-produces a change in the size of the thoracic cavity<br>3. This change in size produces a change in pressure inside the thoracic cavity which causes air to be either inspired or expired<br>4. As the diaphragm contracts it descends and the thorax enlarges. When this occurs, the pressure within the thorax is less than atmospheric pressure and air flows into the lungs. Conversely, when the diaphragm is relaxed, the thoracic cavity is reduced in size and air is forced out of the lungs<br>5. Any disease, trauma or position which alters the pressure within the thoracic cavity will affect lung and normal gas exchange (e.g., pleural effusion). |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

III. Pulmonary Alterations Associated With Cancer And Its Treatment. Each of the following categories cause decreased cross sectional area for gas exchange:

A. Surgical intervention for lung cancer

1. Partial resection of the lung--removal of a diseased part of a lobe of the lung
2. Lobectomy--removal of a lobe of the lung. Right lung is made up of three lobes. Left lung is made up of two lobes
3. Pneumonectomy--the removal of an entire lung

B. Radiation therapy to lungs and/or thorax

1. Any part of the lung that is irradiated will be damaged (Gross, 1977)
2. The severity of damage is related to the total dose delivered, the rate of delivery and the volume of tissue irradiated
3. Radiation pneumonitis usually develops 2-3 months after the completion of therapy. Symptoms are dry cough and dyspnea which tend to resolve although radiologic changes associated with pulmonary fibrosis eventually appear
4. Pulmonary fibrosis increases the thickness of the alveoli membrane and therefore decreases diffusing ability of the gases
5. Symptoms associated with pulmonary fibrosis can be mild or severe, depending upon the above mentioned factors - #2. If severe, may include cyanosis, clubbing of fingers, tachypnea and orthopnea.

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

6. Dactinomycin given as long as thirty days prior to irradiation to lungs has been shown to increase the severity of tissue damage

C. Chemotherapeutic agents causing pulmonary fibrosis (Sostman, 1977)

1. Bleomycin: toxicity related to total dose administered
    a. Total dose below 550 mg, no life-threatening pulmonary disease
    b. 10% of patients who receive greater than 550 mg die from pulmonary toxicity
    c. Toxicity not related to route of administration
    d. Toxicity usually not reversible
2. Methotrexate: toxicity not dose related
    a. Toxicity may be related to frequency of administration
    b. Rare in patients given less than 20 mg/wk
    c. Toxicity may be a hypersensitivity reaction
    d. Reversal of symptoms have been seen both with and without the administration of corticosteroids
    e. After resolution, can continue treatment
3. Busulfan: possibly dose related toxicity
    a. See when administered for greater than an 8 month period

b. Not responsive to corticosteroids

c. Occasionally can have reversal of symptoms when discontinued

4. Other agents associated with pulmonary fibrosis include Cytoxan, 6 Mercaptopurine and Chlorambucil

D. Infection (see section F)

IV. Pulmonary Mechanisms Resulting in Hypoxia

A. Definitions

1. Hypoxia: inadequate supply of oxygen to the tissue

2. Hypoxemia: deficient oxygen content in blood

3. Respiratory failure: inadequate delivery of oxygen to and removal of carbon dioxide from arterial blood ($PaO2<50$; $PaCO2>50$)

4. Alveolar hypoventilation is a reduced rate and depth of breathing leading to low pressures of oxygen at the alveoli.

a. Etiology: sedation, limitation of movement of chest wall, respiratory acidosis

5. Anatomic Shunt: blood that enters the arteries without passing through ventilated areas of the lungs

a. Etiology: Arteriovenus fistula

6. Diffusion abnormality: reduced gas exchange distal and terminal bronchioles

a. Etiology: aspiration, pulmonary edema, pulmonary fibrosis

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | V. Clinical Manifestations of Hypoxia<br>There are receptors in the aorti and carotid bodies which are sensitive to a deficiency in the content of oxygen in the blood (hypoxemia).<br>A. Increased respiratory rate due to the build up of carbon dioxide<br>B. Response of the cardiovascular system is to vaso-constrict via the sympathetic nervous system. Result is increased cardiac output and therefore increased heart rate and increase in contractility leading to an increase in blood pressure<br>C. Patient may also exhibit flaring of the nares with increased inspiratory effort, restlessness, irritability, confusion, cyanosis. Look for cyanosis under tongue or on buccal muscosa; lips and nail beds vary too much<br>D. If hypoxia prolonged and severe, patient will become diaphoretic, lose consciousness and have circulatory collapse<br>VI. Nursing Measures to Prevent and/or Alleviate Pulmonary Complications<br>A. Increase fluid intake (oral or I.V.). Inadequate fluid intake may contribute to mucous secretions becoming thick and tenacious with resultant obstruction of alveoli.<br>B. Frequent movement and positioning which will aid ventilation. Limitation of respiratory movement by poor position which limits chest expansion, muscle weakness due to the debilitation or medications which act on the central nervous system and depress respirations, will be manifested by a stasis and pooling of secretions in the tracheobronchial passages. These secretions are thought to be a prime medium in which pathogens reproduce and grow. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | C. Deep breathing and coughing maneuvers to mobilize secretions. |
| | D. When indicated, suction to aid in removal of secretions. |
| | 1. Wash hands before and after procedure |
| | 2. Use proper technique to avoid trauma to mucosa and spread of infection |
| | 3. Use disposable equipment |
| | 4. Suction nasopharynx and tracheobronchial tree with separate catheters |
| | 5. Discard all opened sterile water bottles after 24 hours. (Pseudomonas contamination risk increases significantly after 24 hours.) |
| | E. Patients who are old, debilitated, have impaired swallowing due to anatomic or functional defects or have altered state of consciousness are particularly prone to developing aspiration pneumonia. |
| | Encourage patient to eat (or feed patient) SLOWLY. Keep patient in sitting position for at least one half hour after meals. |

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C. Discuss the team development. Include in your discussion the team management style, the team functioning (or dysfunction), the communication patterns which emerged.

## V. ETHICAL/LEGAL

A. Identify and describe legal issues which you encountered. Include in your discussion the resolution of these issues and the resources utilized in that resolution.

B. Identify and describe ethical issues or decision making which you encountered. Analyze the ethical issues and the decision making process used in the resolution of these issues.

## VI. PERSONAL STRESS

A. Specify the personal stress experienced while working in hospice setting.

1. identify source of stress
2. indicate how you managed stress or source of stress

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4. communication patterns of family

B. Identify and describe the problems of the family. Include in your description specification of their concerns, their fears, their apparent needs and the interaction effect of these on the family.

C. Specify the strengths of the family.

D. Identify what intervention techniques you used with the family. Include in your discussion the following:

1. use of strengths
2. use of resources
3. education interventions
4. financial planning
5. grief counseling
6. the family as a team member

E. What outside resources did you use in the work with this family? Indicate what resources you identified in the process of working with the family.

IV. TEAM

A. Identify the interdisciplinary team approach as it was applied in your hospice setting.

B. Discuss the roles of interdisciplinary team members.

1. did roles overlap
2. specify role conflict if it occurred
3. clarify what role ambiguity you observed

2. specify interactional problems
3. specify effectiveness of management plan
4. describe patient/family teaching that was initiated relative to pain and symptom management

F. Provide a detailed description of the patient's psychological state. Include psychological needs and reactions to the illness and death.

1. outline and briefly discuss the developmental aspects such as tasks, needs, goals, as well as losses, fears, unfinished business, other needs identified
2. identify and discuss specific coping mechanisms used by patient to work through psychological aspects
3. discuss patient method of expressing grief
4. identify variables which you associate with influencing your patient's needs and responses

G. Provide a brief discussion of your relationship with the patient. Specify the following points in your discussion.

1. description of relationship
2. formation of relationship
3. interaction pattern

## III. FAMILY

A. Describe the family of the patient. Include in your description a discussion of:

1. the family constellation
2. roles of family members
3. relationships within family system

I. HOSPICE

A. Provide a brief discussion of the patient to include the following points.

1. identify the referral source
2. specify the reason for referral
3. define the basic diagnosis at the time of referral
4. define the basic prognosis at the time of referral
5. describe the family/home constellation of the patient at the time of referral

B. Identify and describe the following points relative to your role as a hospice nurse.

1. describe your role with the patient
2. identify your involvement with the patient
3. specify and describe the time period with the patient; include the number of contacts, and type of contact
4. describe communication skills and interventions used in your interaction in your role with the patient/family

II. PATIENT

A. Provide a patient history to include past and present.

B. Specify the patient's physical problems.

C. Identify physiological factors relative to the dying process and the presenting symptoms. Include diagnosis, symptoms and prognosis.

D. Delineate which symptoms are secondary to the dying process and which are related to the pathological process.

E. Discuss interventions used for pain and symptom control.

1. specify results of pain and symptom management, including adverse side effects

# HOSPICE PRACTICUM

The purpose of the practicum is to provide an opportunity to analyze situationally the various aspects of hospice in terms of organization, of your role in the organization, of the patient care and patient care philosophy.

The participant should be provided the opportunity to follow at least one patient/family as their primary nurse from time of admission through death, following the patient during time on inpatient units, when applicable, as well as on home visits, continuing with bereavement follow-up after death. This experience should be closely supervised to provide maximum learning experience and should be accompanied by a written case study describing the experience.

The purpose of the written case study is to provide the learner with an opportunity to apply concepts and skills, in an integrated manner, learned in the didactic portion of the course and during the practicum and from readings in the participant manual. It will allow the learner to synthesize material learned. The end product will provide the learner's supervisor with a written tool upon which evaluation of learning can be based.

Based on materials and knowledge from the hospice modules, the following series of questions are presented to allow a critical analysis of the hospice practicum experience. Critical analysis here asks that you respond to each question in detail, citing situational examples from your practicum experience. Include in your analysis reference to materials or instructional notes on the various modules in hospice.

In the case where a question does not apply to your situation, simply indicate "not applicable." Answer all questions as completely as possible.

Note:

In answering each question first identify the pertinent facts, information or other data relevant to the question. After citing such information, proceed to analyze the situation based on the question. Provide some opinion or conclusion called for in the question based on the facts, the situation and your experience and knowledge.

2. What did you like least about the course? ______________________

3. Which topics or issues would you have liked addressed in this course that were not covered? ______________________

4. In the following space, provide any additional comments or feedback you have on the course or the instructor.

| | Presentor | Content | Relevance to Hospice Nursing |
|---|---|---|---|
| | Poor Satisfactory Excellent | Poor Satisfactory Excellent | Low Medium High |
| 1. Hospice Care Concepts | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 2. Communication Skills | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 3. Concepts of Death, Dying and Grief | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 4. Family Dynamics and Family Counseling | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 5. Managing Personal and Organizational Stress in the Care of the Dying | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 6. Understanding the Process of Dying and the Death Event Itself | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 7. A. Pharmacology | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| B. Pain and Symptom Management | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 8. Interdisciplinary Team Concepts | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 9. Ethical and Legal Issues | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| 10. Other | | | |
| Clergy Panel | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Funeral Home Visit | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |

IV. Open Responses

1. What did you like most about the course? ____________________

____________________________________________

____________________________________________

|  | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |  |
|---|---|---|---|---|---|---|
| 6. The course focused on skills directly transferable to my job | 1 | 2 | 3 | 4 | 5 | NA |
| C. Instructional Materials and Methodology |  |  |  |  |  |  |
| 1. The lecture material was relevant and well presented | 1 | 2 | 3 | 4 | 5 | NA |
| 2. The learning exercises were appropriate | 1 | 2 | 3 | 4 | 5 | NA |
| 3. Small and large group discussions greatly enhanced my learning | 1 | 2 | 3 | 4 | 5 | NA |
| 4. Flip charts and other audiovisual aids (movies) enhanced the module presentation | 1 | 2 | 3 | 4 | 5 | NA |
| 5. The Participant Manual was well designed | 1 | 2 | 3 | 4 | 5 | NA |
| 6. Written materials were an important part of the module | 1 | 2 | 3 | 4 | 5 | NA |
| 7. The Participant Manual will serve as a useful reference when I return to my job | 1 | 2 | 3 | 4 | 5 | NA |

## III. Instructor Effectiveness Content and Relevancy

Using the following chart compare and rate the effectiveness of the instructors for each module and the relevance of each module to the hospice nurse.

|  | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |  |
|---|---|---|---|---|---|---|
| 5. The location of the course made it convenient for me to attend. | 1 | 2 | 3 | 4 | 5 | NA |
| 6. The facilities were pleasant and conducive to learning | 1 | 2 | 3 | 4 | 5 | NA |
| II. Instructional Design |  |  |  |  |  |  |
| A. Course Format |  |  |  |  |  |  |
| 1. The course was too long | 1 | 2 | 3 | 4 | 5 | NA |
| 2. The modules were appropriately sequenced | 1 | 2 | 3 | 4 | 5 | NA |
| 3. The time allocations for the various modules were appropriate | 1 | 2 | 3 | 4 | 5 | NA |
| 4. There was a clear explanation of the relationship between classroom instruction and the practicum | 1 | 2 | 3 | 4 | 5 | NA |
| B. Course Content |  |  |  |  |  |  |
| 1. Written language was clear | 1 | 2 | 3 | 4 | 5 | NA |
| 2. Content was accurate | 1 | 2 | 3 | 4 | 5 | NA |
| 3. Content was relative to my needs | 1 | 2 | 3 | 4 | 5 | NA |
| 4. Case studies and examples were helpful and well utilized | 1 | 2 | 3 | 4 | 5 | NA |
| 5. The course introduced me to new ideas and concepts | 1 | 2 | 3 | 4 | 5 | NA |

## HOSPICE EDUCATION PROGRAM FOR NURSES

### Participant Evaluation Form

### Overall Course Evaluation

Please use the following items to indicate your overall assessment of the presentation of the Hospice Education Program for Nurses. Your assessments and comments will help in the further modification and refinement of the course.

### Overall Course Evaluation

I would rate my overall response to the course as follows:

Circle One for Each Item

| | Needs Improvement | | Satisfactory | | Excellent |
|---|---|---|---|---|---|
| 1. Course design and content | 1 | 2 | 3 | 4 | 5 |
| 2. Instructional materials | 1 | 2 | 3 | 4 | 5 |
| 3. Instructors | 1 | 2 | 3 | 4 | 5 |
| 4. Location and facilities | 1 | 2 | 3 | 4 | 5 |

| I. Course Administration | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree | |
|---|---|---|---|---|---|---|
| 1. I was given plenty of advance notice about the offering of this course | 1 | 2 | 3 | 4 | 5 | NA |
| 2. I was provided a clear picture of the content of the course prior to coming | 1 | 2 | 3 | 4 | 5 | NA |
| 3. The logistics for this course were very well organized | 1 | 2 | 3 | 4 | 5 | NA |
| 4. The mixture of participants (education, experience) was appropriate for the course | 1 | 2 | 3 | 4 | 5 | NA |

## III. LEARNING ENVIRONMENT

Circle the number which reflects your assessment for each of the following six aspects of the learning environment.

| | POOR | | AVERAGE | | EXCELLENT |
|---|---|---|---|---|---|
| 1. Acoustics | 1 | 2 | 3 | 4 | 5 |
| 2. Lighting | 1 | 2 | 3 | 4 | 5 |
| 3. Space | 1 | 2 | 3 | 4 | 5 |
| 4. Temperature | 1 | 2 | 3 | 4 | 5 |
| 5. Ventilation | 1 | 2 | 3 | 4 | 5 |
| 6. Location | 1 | 2 | 3 | 4 | 5 |

## IV. OPEN RESPONSES

1. What did you like most about the module?

2. What did you like least about the module?

3. Which topics or issues would you have liked addressed in this module that were not covered?

4. In the following space, provide any additional comments or feedback you have on the module or the instructor(s). Use the back of this page if necessary.

## II. INSTRUCTOR EFFECTIVENESS

Please rate the instructor(s) for this module on the following dimensions of effectiveness. Place the number corresponding to your ratings in the boxes to the right.

Instructor A (Name) ____________________

Instructor B (Name): ____________________

| | Strongly Disagree | | | | Strongly Agree | | Inst. A | Inst. B |
|---|---|---|---|---|---|---|---|---|
| 1. Presented a clear introduction to module goals, learning objectives and activities | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 2. Defined terms and concepts clearly | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 3. Provided clear instructions for learning exercises | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 4. Demonstrated excellent knowledge and command of concepts and skills being presented | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 5. Provided reasonable opportunities for participants to discuss their ideas and concerns | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 6. Illustrated theoretical concepts with concrete, practical examples | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 7. Answered questions clearly and completely | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 8. Demonstrated sensitivity to needs of participants | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 9. Was well prepared | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |
| 10. Effectively used audiovisual aids | 1 | 2 | 3 | 4 | 5 | NA | ☐ | ☐ |

B. Module Content

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree | |
|---|---|---|---|---|---|---|
| 1. Written language was clear | 1 | 2 | 3 | 4 | 5 | NA |
| 2. Content was accurate | 1 | 2 | 3 | 4 | 5 | NA |
| 3. Content was relative to my needs | 1 | 2 | 3 | 4 | 5 | NA |
| 4. Case studies and examples were helpful and well utilized | 1 | 2 | 3 | 4 | 5 | NA |
| 5. The module introduced me to new ideas and concepts | 1 | 2 | 3 | 4 | 5 | NA |
| 6. The module focused on skills directly transferable to my job | 1 | 2 | 3 | 4 | 5 | NA |

C. Instructional Materials and Methodology

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree | |
|---|---|---|---|---|---|---|
| 1. The lecture material was relevant and well presented | 1 | 2 | 3 | 4 | 5 | NA |
| 2. The learning exercises were appropriate | 1 | 2 | 3 | 4 | 5 | NA |
| 3. Small and large group discussions greatly enhanced my learning | 1 | 2 | 3 | 4 | 5 | NA |
| 4. Flip charts and other audiovisual aids (e.g. movies) enhanced the module presentation | 1 | 2 | 3 | 4 | 5 | NA |
| 5. The participant manual was well designed | 1 | 2 | 3 | 4 | 5 | NA |
| 6. Written materials were an important part of the module | 1 | 2 | 3 | 4 | 5 | NA |
| 7. The module (manual) will serve as a useful reference when I return to my job | 1 | 2 | 3 | 4 | 5 | NA |

# HOSPICE EDUCATION PROGRAM FOR NURSES

## Participant Evaluation Form

## Module Evaluation

Module: ____________________

Date: ____________________

Location and Site: ____________________

### Overall Evaluation of Module

I would rate my overall response to this module as follows:

Circle One for Each Item

| | Needs Improvement | | Satisfactory | | Excellent |
|---|---|---|---|---|---|
| 1. Module design and content | 1 | 2 | 3 | 4 | 5 |
| 2. Instructional materials | 1 | 2 | 3 | 4 | 5 |
| 3. Instructors | 1 | 2 | 3 | 4 | 5 |
| 4. Location and facilities | 1 | 2 | 3 | 4 | 5 |

| I. INSTRUCTIONAL DESIGN (Circle the number that reflects your rating) | Strongly Disagree 1 | Disagree 2 | Neutral 3 | Agree 4 | Strongly Agree 5 | NA |
|---|---|---|---|---|---|---|
| A. Module Format | | | | | | |
| 1. The purpose and goals of the module were clear | 1 | 2 | 3 | 4 | 5 | NA |
| 2. The module content was well organized | 1 | 2 | 3 | 4 | 5 | NA |
| 3. The course had the right combination of theory and skill building practice sessions | 1 | 2 | 3 | 4 | 5 | NA |
| 4. It was easy to follow the course in the Participant Manual | 1 | 2 | 3 | 4 | 5 | NA |
| 5. There was sufficient time to adequately cover the module content | 1 | 2 | 3 | 4 | 5 | NA |

## PRE-TEST/POST-TEST SUMMARY SHEET

| Participant | Pre-test Score | Post-test Score | Learning Gain |
|---|---|---|---|
| 1. | | | |
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| 26. | | | |
| 27. | | | |
| 28. | | | |
| 29. | | | |
| 30. | | | |
| Average | | | |

## ANSWER KEY

## Test Form B

1. A B [✓ C] D
2. A B C [✓ D]
3. A [✓ B] C D
4. [✓ A] B C D
5. A B C [✓ D]
6. A B C [✓ D]
7. [✓ A] B C D
8. [✓ A] B C D
9. A B C [✓ D]
10. [✓ A] B C D
11. A B [✓ C] D
12. A [✓ B] C D
13. A B C [✓ D]
14. A [✓ B] C D
15. A B C [✓ D]
16. A [✓ B] C D
17. [✓ A] B C D
18. A [✓ B] C D
19. A B [✓ C] D
20. A B [✓ C] D
21. A B C [✓ D]
22. A B C [✓ D]
23. A B C [✓ D]
24. A B [✓ C] D
25. [✓ A] B C D
26. A B [✓ C] D
27. A B [✓ C] D
28. A B C [✓ D]
29. A B [✓ C] D
30. [✓ A] B C D
31. A [✓ B] C D
32. [✓ A] B C D
33. A [✓ B] C D
34. A B [✓ C] D
35. A [✓ B] C D
36. A B C [✓ D]
37. A [✓ B] C D
38. A B [✓ C] D
39. [✓ A] B C D
40. A [✓ B] C D
41. [✓ A] B C D
42. [✓ A] B C D
43. A [✓ B] C D
44. A B [✓ C] D
45. A B C [✓ D]
46. [✓ A] B C D
47. A [✓ B] C D
48. A B C [✓ D]
49. A [✓ B] C D
50. A [✓ B] C D

# ANSWER KEY

## TEST FORM A

1. A B [✓ C] D
2. A [✓ B] C D
3. A B C [✓ D]
4. A B [✓ C] D
5. [✓ A] B C D
6. A [✓ B] C D
7. A B C [✓ D]
8. A [✓ B] C D
9. A B C [✓ D]
10. A B [✓ C] D
11. A B [✓ C] D
12. [✓ A] B C D
13. A B C [✓ D]
14. A B C [✓ D]
15. A B C [✓ D]
16. A B C [✓ D]
17. A B [✓ C] D
18. A B [✓ C] D
19. A B [✓ C] D
20. A B [✓ C] D
21. A [✓ B] C D
22. A [✓ B] C D
23. A B [✓ C] D
24. [✓ A] B C D
25. A [✓ B] C D
26. A [✓ B] C D
27. A B [✓ C] D
28. A [✓ B] C D
29. A [✓ B] C D
30. A [✓ B] C D
31. A [✓ B] C D
32. A [✓ B] C D
33. A B [✓ C] D
34. A B [✓ C] D
35. A [✓ B] C D
36. A B C [✓ D]
37. A B C [✓ D]
38. A B C [✓ D]
39. A [✓ B] C D
40. A [✓ B] C D
41. A B C [✓ D]
42. A B [✓ C] D
43. A B [✓ C] D
44. A B C [✓ D]
45. [✓ A] B C D
46. A B [✓ C] D
47. A [✓ B] C D
48. A B [✓ C] D
49. [✓ A] B C D
50. A B [✓ C] D

# ANSWER SHEET

Name or I.D. Code No. ______________________ Check one: Pre-test ____

Post-test ____

Date ______________

Location ______________________________ Check one: Test Form A ___

Test Form B ___

*Darken with a pen or pencil the letter that best answers the question.*

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| 1. | A | B | C | D | 26. | A | B | C | D |
| 2. | A | B | C | D | 27. | A | B | C | D |
| 3. | A | B | C | D | 28. | A | B | C | D |
| 4. | A | B | C | D | 29. | A | B | C | D |
| 5. | A | B | C | D | 30. | A | B | C | D |
| 6. | A | B | C | D | 31. | A | B | C | D |
| 7. | A | B | C | D | 32. | A | B | C | D |
| 8. | A | B | C | D | 33. | A | B | C | D |
| 9. | A | B | C | D | 34. | A | B | C | D |
| 10. | A | B | C | D | 35. | A | B | C | D |
| 11. | A | B | C | D | 36. | A | B | C | D |
| 12. | A | B | C | D | 37. | A | B | C | D |
| 13. | A | B | C | D | 38. | A | B | C | D |
| 14. | A | B | C | D | 39. | A | B | C | D |
| 15. | A | B | C | D | 40. | A | B | C | D |
| 16. | A | B | C | D | 41. | A | B | C | D |
| 17. | A | B | C | D | 42. | A | B | C | D |
| 18. | A | B | C | D | 43. | A | B | C | D |
| 19. | A | B | C | D | 44. | A | B | C | D |
| 20. | A | B | C | D | 45. | A | B | C | D |
| 21. | A | B | C | D | 46. | A | B | C | D |
| 22. | A | B | C | D | 47. | A | B | C | D |
| 23. | A | B | C | D | 48. | A | B | C | D |
| 24. | A | B | C | D | 49. | A | B | C | D |
| 25. | A | B | C | D | 50. | A | B | C | D |

46. Synthesizing all the information in the case study, Mr. G.'s symptoms of demandingness, hostility, rebelliousness, and refusal to obey doctors' orders strongly indicate that one of his major fears currently is:

a. the fear of loss of control
b. the fear of the unknown
c. the fear of loss of family and friends
d. the fear of suffering and pain

47. A patient requests that the physician give him something that would end his pain forever. Which type of euthanasia does this request represent?

a. passive/voluntary euthanasia
b. active/voluntary euthanasia
c. active/involuntary
d. passive/involuntary

48. According to Yarling, which of the following rights could the nurse claim if a physician objected to her telling a patient the truth given certain circumstances?

a. a legal right
b. a technical right
c. a human right
d. a moral right

49. Which of the following concepts best describe some components of a moral/ethical situation?

a. values, laws, rights
b. values, conflict, choices
c. moral principles, policies, rules
d. choices, laws, relationships

50. You are the hospice nurse in a home where Mrs. W. is dying from metastatic cancer of the bowel. She sometimes refuses her pain medication and you tell her that as a nurse you think she should take it. What ethical relationship does this represent?

a. collegial
b. priestly/paternalistic
c. contractual/convenantal
d. engineering

inoperable brain tumor. Mr. G. is an accountant employed by a large public accounting firm. He is married and the father of three children: a girl 11, and two sons, 8 and 4. His ethnic background is English and German. His father died nine years ago following a painful and lingering illness of lung cancer.

Since he has been hospitalized, Mr. G. has been hostile, demanding, rigid and rebellious. He has been increasingly intolerant of any change in routine, although he has always been characteristically very self-controlled and composed. He has cluttered up his hospital room with piles of books and papers pertaining to his accounting business and disregards doctors' orders to relax and put his work aside to decrease his stress. With his wife he has become verbally abusive, something which never occurred before. His relationships with the nurses are marked by his demandingness and irritability.

Armed only with the information in this case study you are asked to see Mr. G. The following questions pertain to the course of action you will take with this patient.

43. Mr. G.'s youngest son may erroneously think his father is sick because of the son's thoughts and actions. This belief reflects:

    a. a desire to punish himself
    b. magical thinking
    c. anger and shame
    d. past experiences with loss

44. Given the research, Mrs G. can be expected to:

    a. remarry within six months of her husband's death
    b. have a more intense grief reaction to the death of Mr. G. than her mother-in-law
    c. experience some physical symptoms after death
    d. have a lasting change in social interaction following Mr. G.'s death

45. Given Mr. G.'s stage in life, some of his main concerns about dying may be expected to center around:

    a. feelings about being deprived of life when on the threshold of experiencing it fully
    b. feelings about having life interrupted at the moment of its fulfillment
    c. feelings about trying to make meaning out of one's own life and its accomplishments
    d. feelings about those left behind and responsibilities that will be left unmet

37. Why are phenothiazines commonly used as narcotic adjuncts to chronic pain?

    a. antianxiety activity
    b. antiemetic activity
    c. analgesic activity
    d. a and b

38. Which of the following drugs is more appropriate in severe, chronic pain?

    a. morphine plus cocaine
    b. heroin plus alcohol
    c. morphine plus a phenothiazine
    d. heroin plus cocaine plus a phenothiazine

39. Which of the following narcotic analgesics is usually not preferred in chronic pain due to the drug's short duration of action?

    a. meperidine
    b. morphine
    c. aspirin
    d. methadone

40. With regard to the four types of death, the goal of hospice is to:

    a. separate the four types of death
    b. assist the four types of death to occur as sequentially and coincidentally as possible
    c. help the family cope with the last two types of death
    d. prevent psychological death from occurring

41. The main criticism about "stage" theories is that:

    a. they imply that there is an invariate and sequential grief process experienced by all people
    b. grief is the reaction to any loss, not just loss through death
    c. it is more helpful to think of grief reactions to loss, not stages
    d. they are too simplistic

42. One of the most difficult aspects of grief that the majority of mourners must struggle with is:

    a. ambivalence and hostility toward the deceased
    b. hallucinations of the deceased
    c. depression over the loss
    d. physiological manifestations of grief

Read the following case study and then proceed to the questions.

Case Study

Mr. G. is a thirty-eight year old man who has been hospitalized with an

Mr. B. is a 56 year old white male with advanced multiple sclerosis which is causing severe pain. His disease is in the terminal stage. He is in pain, anxious, depressed and belligerent.

32. You are asked to help plan his symptom management. Which drug(s) would you initially recommend?

    a. aggressive narcotic analgesic doses
    b. low narcotic analgesic doses
    c. aggressive sedative therapy
    d. aggressive antianxiety drug therapy

33. Mr. B. slept for 22 hours following a single oral dose of 15 mg methadone. His pulse and respiratory rates were normal. The probable cause of the long sleep is:

    a. too high a dose of narcotic
    b. sleep deficit
    c. poor renal function
    d. failure to use cocaine concurrently

Mrs. S. is a 65 year old lady with advanced hepatoma. She has lost 50 of her normal 140 pounds and her muscle mass is severely wasted. She has a history of grand mal epilepsy which is controlled with phenytoin.

34. She can no longer take her drugs orally. What route would you suggest for her narcotic and phenothiazine?

    a. IM
    b. IV
    c. PR
    d. SC

35. Mrs. S. would like to eat but has no appetite. Which of the following groups of drugs may help her anorexia?

    a. barbiturates
    b. steroids
    c. antianxiety drugs
    d. antidepressants

36. Mrs. S. is experiencing phenytoin toxicity. An explanation for this is:

    a. she needs a lower dose due to her weight loss
    b. she needs a lower dose due to her liver disease
    c. she needs a higher dose due to her liver disease
    d. a and b

26. "You say everything's fine, but your voice sounds very angry and upset." is an example of what intervention:

a. summarizing
b. paraphrasing
c. confrontation
d. encouraging verbal communication

27. If you are experiencing stress due to your difficulty with setting effective limits and find yourself being manipulated into positions and roles you find unbearable, you could probably benefit from:

a. Benson's technique
b. biofeedback
c. assertiveness training
d. progressive relaxation

28. Professional stress may result in:

a. isolation from other staff
b. overbonding with other staff
c. increased conflicts between staff
d. all of the above

29. Which of the following is not a meditative technique?

a. TM
b. Benson's technique
c. progressive relaxation
d. CSM

30. Which of the following is not a stage of the General Adaptation Syndrome?

a. the trigger stage
b. the stage of resistance
c. the alarm reaction
d. the stage of exhaustion

31. In White's "organizational family system" model of examining professional stress, dysfunctional responses to stress are viewed as:

a. a problem of skill deficiency (stress management skills)
b. a breakdown in the relationship between the organization and the individual
c. a problem of individual psychopathology
d. all of the above

20. Mr. S. rates his pain as 2-4 (on the 0-10 scale) but insists on the need for stronger medication (a narcotic) or some new plan to relieve his pain. The basis for your response is:

a. that pain at 2 does not require further intervention
b. that Mr. S. is being unrealistic in expecting total relief
c. that Mr. s's lack of willingness to tolerate even pain at 2 directs plan
d. that the risks of narcotic use are not warranted in this situation

21. When a learning group has reached the mature stage of development, it is appropriate for the hospice nurse to emphasize the following teaching interventions:

a. briefing and instruction
b. facilitation and team building
c. briefing, feedback, and team building
d. monitoring, feedback, and modeling

22. _______________help(s) clear the way for new topics of discussion between the patient and nurse.

a. confrontation
b. paraphrasing
c. closed questions
d. summarizing

23. "Such as?" is an example of:

a. a minimal lead
b. an open question
c. accurate verbal following
d. all of the above

24. _______________ is the most consistently used teaching skill utilized by the hospice nurse.

a. briefing
b. facilitation
c. modeling
d. monitoring

25. "Why" questions should be avoided during interviews with patients/families because such questions:

a. imply scolding, fault finding, and dissatisfaction
b. put words in the mouth of the patient/family member
c. are hard to answer and rarely produce any beneficial information
d. prevent the patient/family members from expressing deep emotion

14. The most common type of bladder disorder encountered in hospice care is:

    a. spastic bladder
    b. flaccid bladder
    c. uninhibited bladder
    d. all are essentially equal

15. Mr. H has congestive heart failure, albuminemia secondary to malnourishment and lymphatic obstruction in his inguinal nodes. Daily assessment should include:

    a. measure each leg with tape
    b. palpate for edema
    c. dorsiflex the foot
    d. all of the above

16. Mr. U is so weak that he can only manage to ingest four or five bites of food at each meal. You would do all but which of the following:

    a. change Mr. U's diet to 6 meals/day
    b. encourage Mr. U to drink 30 cc $H_2O$/hour
    c. give Mr. U's analgesic with Ensure
    d. utilize many casserole type dishes

17. Tom is severely anorexic and is losing 22 lbs/wk. Based on knowledge of the various factors which contribute to anorexia, the following is the most appropriate plan:

    a. hi cal, hi protein breakfast with snacks q 3 h till 11 pm
    b. hi protein, hi calorie diet - 3 meals/day
    c. mechanical soft diet with milk shakes at 10 am and 2 pm
    d. hyperalimentation with full liquid supplements 6 times/day

18. Daily assessment of Mr. K., who is at great risk of thromboembolic problems, should include:

    a. check clotting times and gentle palpation of path of veins in legs
    b. dorsiflexion of each foot and examination of the chest and lungs
    c. temperature and measurement of each leg
    d. palpate peripheral pulses and x-ray chest

19. Gentamicin Sulfate (Garamycin), Kanamycin (Kantrex), Polymyxin B and Amphotericin B have the following serious side effects in common:

    a. fever
    b. hypersensitivity
    c. nephrotoxicity
    d. vomiting

8. Delayed vomiting is associated with:

   a. low, small bowel obstruction
   b. high, small bowel obstruction
   c. low, large bowel obstruction
   d. high, large bowel obstruction

9. Inadequate cerebral blood flow can account for which symptom?

   a. inappropriate laughter
   b. picking at bed clothes
   c. darting from one object to another
   d. all of the above

10. Rigor mortis begins within ___________ after death.

   a. 2-4 hours
   b. 4-6 hours
   c. 6-8 hours
   d. 8-10 hours

11. Dr. Cicely Saunders is associated with:

   a. care of the terminally ill in the United States
   b. the publication entitled, "Journal of Thanatology"
   c. St. Christopher's Hospice
   d. all of the above

12. Which of the following individuals are associated with reform of care of the terminally ill?

   1. Dr. Cicely Saunders
   2. Dr. William Osler
   3. Dr. Elisabeth Kübler-Ross
   4. Ida Orlando

      a. 1 & 2
      b. 1 & 3
      c. 2 & 3
      d. 2 & 4

13. The first hospice in the United States was started in:

   a. Marin, California
   b. Boulder, Colorado
   c. Riverside of New Jersey
   d. New Haven, Connecticut

## FORM B POST-TEST

1. "Children must be protected from painful experiences (such as funerals)." is an example of:

   a. a cultural prohibition
   b. family homeostasis
   c. a family rule
   d. family coalitions

2. The exclusion of children from family mourning rituals may:

   a. give the child very distorted ideas of illness and death
   b. leave the child vulnerable to physical and emotional dysfunction
   c. lead to a belief by the child that they are responsible for the death
   d. all of the above

3. In families that have experienced the death of a child, the "replacement child syndrome" is marked by:

   a. parental detachment from all the remaining siblings
   b. the idealization of the dead child
   c. the overprotection of all the remaining siblings
   d. none of the above

4. In which of the following family types would you expect to see the most difficult adjustments to the death of a family member?

   a. the enmeshed family system
   b. the open family system
   c. the disengaged family system
   d. the differentiated family system

5. Which of the following factors may effect functioning of hospice team members?

   a. location of the hospice (hospital, hospice or community)
   b. administrative constraints
   c. fiscal factors
   d. all of the above

6. Membership of the hospice care team will be influenced by:

   a. the patient's needs
   b. availability of professional staff
   c. cost constraints
   d. all of the above

7. If patient has respiratory distress the following may be used:

   a. change of position to sitting
   b change of position to a lying position
   c. ambulate patient
   d. none of the above

46. Which of the following responses would be the most appropriate for you to undertake immediately?

    a. speak with Mr. G.'s family and friends to determine in what ways he has changed and how they think he could use professional help
    b. tell Mr. G. that you are familiar with the needs of dying patients and that you want to talk with him about his dying
    c. encourage Mr. G. to speak about what he is feeling if he wishes and do a differential diagnosis of the fears of dying to see which are most salient for him at the present time
    d. bring in Mr. G.'s wife and try to do some supportive marital counseling with them in order to maximize their time together

47. Which of the following statements best reflects the purpose of the ANA Code for Nurses with Interpretive Statements?

    a. provide the nurse with answers to specific ethical dilemmas
    b. provide general guidelines for ethical duties and obligations of the nursing profession
    c. provide a basis for the nurse to claim certain legal rights for professional practice
    d. provide nurses with rights to make ethical decisions for patients

48. Who should make decisions for the competent patient who is terminally ill to enhance the principles of autonomy and nonmaleficence?

    a. the physician
    b. the physician and nurse
    c. the patient
    d. the patient's family

49. Which of the following are examples of ethical issues and dilemmas in health care generally and in caring for the terminally ill?

    a. coercion, autonomy, human rights
    b. professional practice and licensure laws
    c. state legislation of the "living will"
    d. hospital policy on medication errors

50. The nurse and patient discuss both of their values and goals for use of pain control medication when the patient is first admitted to a palliative care unit. Which ethical relationships does this best represent?

    a. priestly/paternalistic
    b. engineering
    c. contractual/covenantal
    d. collegial

Read the following case study and then proceed to the questions.

Case Study

Mr. G. is a thirty-eight year old man who has been hospitalized with an inoperable brain tumor. Mr. G. is an accountant employed by a large public accounting firm. He is married and the father of three children: a girl 11, and two sons, 8 and 4. His ethnic background is English and German. His father died nine years ago following a painful and lingering illness of lung cancer.

Since he has been hospitalized Mr. G. has been hostile, demanding, rigid, and rebellious. He has been increasingly intolerant of any change in routine, although he has always been characteristically very self-controlled and composed. He has cluttered up his hospital room with piles of books and papers pertaining to his accounting business and disregards doctors' orders to relax and put his work aside to decrease his stress. With his wife he has become verbally abusive, something which never occurred before. His relationships with the nurses are marked by his demandingness and irritability.

Armed only with the information in this case study you are asked to see Mr. G. The following questions pertain to the course of action you will take with this patient.

43. Hospitalizations such as the current one of Mr. G. usually signal the beginning of some degree of _______________ death.

    a. physiological
    b. biological
    c. social
    d. psychological

44. After Mr. G.'s death, Mrs. G. may need some help expressing ___________ resulting from the way Mr. G. treated her during his illness.

    a. depression
    b. anxiety
    c. guilt
    d. anger

45. Because of his high need for control, Mr. G. may have some difficulty becoming appropriately _______________ with the nurse as his regression deepens and his illness intensifies.

    a. dependent
    b. hostile
    c. demanding
    d. vulnerable

36. Which of Mr. S's drugs is apt to cause constipation:

a. the narcotic
b. the narcotic and phenothiazine
c. the anticholinergic agent
d. the narcotic, phenothiazine and anticholinergic agent

37. What drug therapy of the depression associated with chronic pain is usually indicated:

a. monoamine oxidase inhibitors
b. tricyclic antidepressants
c. analgesics plus alcohol
d. none

38. What percentage of cancer patients experience chronic, severe pain:

a. 100%
b. 75%
c. 50%
d. <50%

39. Marijuana might be considered in managing nausea due to:

a. uremia
b. chemotherapy which does not respond to phenothiazine
c. radiation therapy
d. elevated intracranial pressure

40. Restriction of interest in the external world, egocentricity, dependence, hypochondriasis and altered time sense are all examples of the defense mechanism of:

a. suppresion
b. regression
c. denial
d. depersonalization

41. There has been literature that suggests the death of one's ______________ provokes the most intense grief reactions.

a. spouse
b. parent
c. sibling
d. child

42. The two most difficult emotions to deal with in grief are:

a. guilt and despair
b. anger and depression
c. anger and guilt
d. denial and depression

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31. McLean's model for examining one's stress response examines what factor(s)?

a. organizational context
b. stressor
c. individual vulnerability
d. all of the above

Ms. G. is a 32 year old divorced attorney and mother of two boys aged 12 and 8. She has advanced, irreversible disease and is not expected to live more than six months longer. She is also somewhat withdrawn and depressed.

32. Ms. G is extremely anxious in spite of good pain control. Which of the following is indicated in her treatment plan for anxiety?

a. antianxiety drugs
b. a social work consult regarding her children
c. a legal consult regarding the disposition of her practice
d. all of the above

33. What therapy would you consider for her depression?

a. tricyclic antidepressants
b. monoamine oxidase inhibition
c. management of the anxiety
d. an antihistaminic antiemetic

Mr. S. is a 68 year-old male with metastatic carcinoma of the lung. His pain and anxiety are being successfully managed with morphine on a regularly scheduled basis plus prochlorperazine. He is also receiving an anticholinergic agent to lessen the "rattled breathing" he experienced due to secretion in his throat.

34. Mr. S.'s urine excretion has decreased dramatically. The most probable cause is:

a. the cancer
b. liver dysfunction
c. anticholinergic activity
d. pain

35. The most appropriate management for his urinary retention is:

a. lower the narcotic dose
b. a cholinergic drug - bethanechol
c. increase the narcotic dose
d. catheterize him

25. "Do you feel tired today?" is an example of:

   a. minimal lead
   b. a closed question
   c. reflection of feeling
   d. none of the above

26. One assesses the need for ________________ through identifying discrepancies and contradictions in the patient's statements and behavior. The intervention missing in the above statement is:

   a. paraphrase
   b. confrontation
   c. reflection of feeling
   d. all of the above

27. The first stage in Harper's model describing the coping sequence of those caring for the dying is:

   a. depression
   b. deep compassion
   c. intellectualization
   d. overinvolvement

28. Which of the following factors is the best predictor of one's ability to manage stress in the hospice care setting?

   a. one's values and beliefs
   b. one's prior history of stress management
   c. one's professional training
   d. one's current physical and emotional health

29. A stress management ritual that signals to ourselves and others that one part of our life is ending and another part is beginning is called a:

   a. time-out period
   b. decompression routine
   c. rite of transition
   d. all of the above

30. Which of the following terms refer to those situations, conditions, or agents that produce stress?

   a. stress factors
   b. stressors
   c. stress response
   d. none of the above

19. Since infection aggravates the problem of incontinence, each of the following measures is important to prevent urinary tract infections except:

    a. avoid indwelling catheter if possible
    b. encourage frequent emptying of the bladder (q 4-6 h)
    c. limit fluid intake to 1000 - 1500 cc/day
    d. teach patient/family proper wiping and peri-care

20. The measure of pain which has the highest validity is:

    a. heart rate
    b. cortisol output
    c. patient's reports
    d. activity level

21. The hospice nurse can best validate assumptions about patient needs by:

    a. using silence and physical presence
    b. using paraphrasing and reflection of feeling
    c. using open questions
    d. using effective summarizing

22. The premature use of ______________ and ______________ may make the patient anxious and threaten the relationship.

    1. confrontation
    2. reflection of feeling
    3. self disclosure
    4. problem solving

        a. 1 and 2
        b. 1 and 3
        c. 2 and 4
        d. 3 and 4

23. The force field analysis step of the problem solving process:

    a. helps define the problem
    b. helps identify the direction of desired change
    c. helps identify factors working for and against change
    d. helps assess the outcome of the action plan

24. In working with groups of patients/family members, staff and volunteers in a teaching role; the hospice nurse should be aware of the following three stages of group development.

    a. dependence, testing, conjoint functioning
    b. mistrust, cohesion, independence
    c. testing, cohesion, collaboration
    d. fear, testing, trust

13. Reform of care for terminally ill patients was necessary because:

    a. care of the terminally ill was too complex
    b. too little was known about terminal disease processes
    c. there was no role for terminally ill patients in research or education within our highly technologized institutions
    d. the disease was being treated rather than the person

14. Ms. L. is being discharged to the home care unit. She has severe osteoporosis. She has suffered several pathologic fractures in the past two years. In assessing the home, the home care nurse should recommend:

    a. place turning sheet on the bed
    b. purchase of low heeled, non-slip shoes
    c. removal of all throw rugs
    d. all of the above

15. The most frequent primary cause of death in cancer patients is:

    a. cachexia
    b. hemorrhage
    c. multiple organ failure
    d. pneumonia

16. Mr. J. has severe stomatitis and esophagitis. Appropriate intervention would include:

    a. clear liquid diet
    b. lemon-glycerine swabs prn
    c. Darvon compound 65 mg q 4 h prn
    d. viscous xylocaine P.O. q 2-3 h prn

17. Anorexia is the result of all of the following except:

    a. amines produced during stress may suppress the appetite center
    b. decreased taste may eventually result in slowed digestion with decreased appetite
    c. the anaerobic metabolism of the tumor cell may raise the basal metabolic rate of the host
    d. frequent associations of food with nausea/vomiting may develop a conditioned food aversion

18. Decubiti occur frequently in bedridden patients. The best approach is:

    a. application of skin toughening agent to all boney prominences
    b. flotation mattress on all beds
    c. turn patient q 1-2 hrs
    d. whirlpool baths daily

6. In a four person nuclear family, there are __________ dyadic relationships that will be altered by the terminal illness of one of the family members.

a. four
b. six
c. eight
d. twelve

7. Nausea and vomiting may be the consequence(s) of:

a. malignancy per se
b. side effects of treatment
c. obstruction
d. all of the above

8. The vomiting of fecal smelling substance is indicative of:

a. small bowel obstruction
b. large bowel obstruction
c. a medication reaction
d. acute gastritis

9. Assessment of adequate cerebral blood flow can be determined by the patient's orientation to:

a. place
b. time
c. event
d. all of the above

10. Liver mortis is the color change after death which occurs in:

a. independent positions
b. exposure positions
c. dependent positions
d. all of the above

11. How many forms of hospices have evolved?

a. three
b. four
c. five
d. six

12. The hospice philosophy of care mandates that:

a. the focus be on the patient/family
b. that every life sustaining attempt be utilized prior to admission to a hospice
c. there be no focus on spirituality
d. there are times when you can do no more for a patient

## FORM A PRE-TEST

Which of the following are necessary components of interdisciplinary teamwork:

1. role expectations
2. role overlap
3. leadership
4. role conflict
5. communication
6. role congruence

a. 1, 2 and 4
b. 2, 3 and 6
c. 1, 3 and 5
d. all of these

2. Leadership in which an individual uses their position as a legitimate basis for controlling and directing the group's function is termed:

a. democratic
b. authoritarian
c. oligarchical

3. Scapegoating within the family experiencing the impending death of one of the family members can serve to:

a. prevent the expression of resentments against the dying person
b. bring the family closer together
c. deny the reality that the family member is dying
d. all of the above

4. Studies have shown that in families experiencing the death of a child, as many as ______ per cent of family members react to the death strongly enough to require psychiatric help.

a. 30
b. 40
c. 50
d. 60

5. The high mortality rate of widows and widowers following the deaths of their spouses may be closely related to the concept of:

a. fusion
b. family homeostasis
c. family life cycles
d. differentiation

# APPENDIX B

## Evaluation

This section describes the evaluation procedures and instruments that have been designed for the Hospice Education Program for Nurses. We will first look at the administration of the pre-tests and post-tests and conclude by discussing the two Participant Evaluation Forms. To prepare for the evaluation procedures, you must reproduce an appropriate number of forms and answer sheets for participants.

### Pre-tests and Post-tests

Two tests (Form A and Form B) have been developed to measure the knowledge of participants in key content areas of the course. By comparing participant scores on the pre-test, which is administered the first morning of the course, with scores on the post-test given at the conclusion of training, one can begin to make assumptions about the learning gains acquired during participation in the course.

### Instructions for Test Administration

Either Form A or Form B can be used as a pre-test, with the alternate form as a post-test. One form should be used for all participants, as the pre-test, and the other as the post-test. When you administer the pre-test, inquiries about test items should not be answered. It should be explained that the course will provide the answers in a way that will enable participants to understand what is correct, and, more important, why it is correct. After post-testing, feel free to discuss any and all items on either the pre-test or the post-test.

Instructions should be verbalized as printed below. The time allowed to complete the test is 30 minutes.

### INSTRUCTIONS:

This test is being given so that we may measure your knowledge of course material both before and after completing the course. The test contains multiple choice questions. On the answer sheet darken with a pen or pencil the letter that best answers the question. You have 30 minutes to complete the test.

### Participant Evaluation Forms

There are two forms that have been designed to elicit the participant's evaluation of the Hospice Education Program for Nurses. The first form - The Participant Evaluation Form/Module Evaluation - is to be administered at the conclusion of each of the nine course modules. The form is designed to generate feedback on the instructional design and content, the instructional materials, and the learning environment that can be utilized to improve future presentations of the module. The second form - The Participant Evaluation Form/Overall Course Evaluation - is to be administered at the end of the course and is designed to generate feedback on the overall design, organization and presentation of the course.

## PRACTICUM PLANNING/EVALUATION CHECKLIST

| MODULE | PRACTICUM EXPECTATIONS | COMPLETION OF ACTIVITY ☑ | (circle one number)<br>DEMONSTRATED LEVEL OF KNOWLEDGE AND EXPERTISE<br>1= unsatisfactory level of expertise<br>5= satisfactory<br>10= exceptional level of expertise |
|---|---|---|---|
| IX. Ethical and Legal Issues (cont.) | ☐ use the interdisciplinary team to help explore and resolve legal and ethical issues | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
|  | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
|  | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |

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|---|---|---|---|
| VIII. Interdisciplinary Team | During the practicum, the nurse was able to: | | |
| | ☐ actively participate in interdisciplinary team meetings. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ identify and describe the roles of hospice team members. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ identify areas of role overlap and role conflict among team members. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ solicit the assistance and involvement of other team members in patient/family care situations. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| IX. Ethical and Legal Issues | During the practicum, the nurse was able to: | | |
| | ☐ identify and articulate ethical issues and dilemmas encountered in hospice nursing | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ identify and articulate legal issues in hospice nursing | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |

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|---|---|---|---|
| VII B. Pain (cont.) | ☐ assess patient condition and prescribe interventions which are appropriate to patient/family needs. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ recognize signs and symptoms of infection and prevent cross contamination with other patients and staff. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ assess, plan and implement care for symptoms of pain, anorexia, nausea/vomiting, taste disturbances, stomatitis, constipation, diarrhea, incontinence, edema, thrombophlebitis, decubiti, pathologic fractures, infection, fatigue and dyspnea. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ evaluate the effectiveness of nursing measures in relieving symptoms. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrate non-medicinal pain control techniques. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ adapt patient care procedures to the home setting. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |

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|---|---|---|---|
| VII A. Pharmacology (cont.) | ☐ describe rationale for regularly scheduled and relatively high narcotic doses rather than prn dosing in severe chronic pain of physical origin. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ identify the primary side effects of the drugs most frequently utilized to manage symptoms of advanced cancer. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ analyze role of anxiety in patient pain | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ report the equipotent dosages of the most frequently used analgesic drugs in the program. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ describe the role of anti-inflamatory drugs in the management of severe chronic pain of physical origin. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| VII B. Pain and Symptom Management | During the practicum, the nurse was able to: | | |
| | ☐ conduct a mini pain assessment | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |

PRACTICUM PLANNING/EVALUATION CHECKLIST

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|---|---|---|---|
| VI. The Process of Dying and the Death Event Itself | During the practicum, the nurse was able to: | | |
| | ☐ recognize the physiological indicators of dying and death on a cellular and system wide level. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ recognize Cheyne Stokes breathing and the "death rattle." | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ recognize cardiac arrythmia. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ recognize symptoms of severe dehydration and starvation. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ identify and explain to family predictable physiological postmortem changes. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| VII A. Pharmacology | During the practicum, the nurse was able to: | | |
| | ☐ identify and describe their own beliefs about pain control. | ☐ | 1 2 3 4 5 6 7 8 9 10 |

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|---|---|---|---|
| V. Stress (cont.) | ☐ demonstrated the effective use of time-out periods, supervisory supports, stress management techniques, etc. to manage professional stress. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ maintained an adequate replenishment and support network. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ used supervisory and peer supports to grieve the loss of patients. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrated a sensitivity to the stress responses of professional peers. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ avoided or regulated overinvolvement (time) and overinvestment/attachment (emotional) to program and patients | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ avoided prolonged emotional distancing maneuvers from patients and family members | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |

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|---|---|---|---|
| IV. Family (cont.) | ☐ assist the family in reviewing and/or redefining family roles and family rules following the death of the patient. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ facilitate and enhance the involvement of family members in the physical and emotional care of the patient. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ mobilized community resources to assist families. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ assisted the family in the resolution of grief folloiwng the death of the patient. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| V. Managing Personal and Organizational Stress in the Care of the Dying | During the practicum, the nurse: | | |
| | ☐ identified their own early warning signs of professional stress | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ maintained an adequate balance between their work life and personal life | ☐ | 1 2 3 4 5 6 7 8 9 10 |

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|---|---|---|---|
| III. Concepts of Death, Dying and Grief (cont.) | ☐ discuss his/her own expereinces and feelings with death. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| IV. Family Dynamics and Family Counseling | During the practicum, the nurse was able to: | | |
| | ☐ describe the rationale for family centered hospice care | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ identify and describe the impact of dying and death on the patient's family system. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ facilitate meetings with the patient and family as part of the family assessment process. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ prepare a hospice care plan that included strategies for addressing the needs of the total family system. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ identify and intervene in the family scapegoating process | ☐ | 1 2 3 4 5 6 7 8 9 10 |

## PRACTICUM PLANNING/EVALUATION CHECKLIST

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|---|---|---|---|
| II. Communication Skills (cont.) | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| III. Concepts of Death, Dying and Grief | During the practicum, the nurse was able to: | | |
| | ☐ define and recognize signs of anticipatory grief. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ identify physiological and psychological manifestations of grief. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ identify and describe social and psychological factors that inhibit appropriate grieving. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ demonstrate interventions to facilitor appropriate grieving. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ identify the major tasks of the dying patient. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ recognize the defense mechanisms of the dying patient. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ assist families in explaining death and dying to children in the family. | ☐ | 1 2 3 4 5 6 7 8 9 10 |
| | ☐ assess the needs of the bereaved in a follow-up visit in the home. | ☐ | 1 2 3 4 5 6 7 8 9 10 |

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|---|---|---|---|
| II. Communication Skills | The nurse consistently demonstrated the following skills during patient/family interviews. | | |
| | ☐ regularly validated assumptions about patient/family needs. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrated sensitivity and respect for culture, and lifestyles of patient/family. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrated effective attending behaviors. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ performed accurate paraphrasing and reflection of feeling. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrated well timed and appropriate level of self-disclosure. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrated verbal and non-verbal skills in providing reassurance and support. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ effectively utilized the problem solving process with patients/family. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrated teaching skills with other interdisciplinary team members. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ taught family members and volunteers patient care techinques. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ demonstrated use of "silence" and physical presence with patient/family. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |

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|---|---|---|---|
| I. Hospice Care Concepts | The nurse performed or demonstrated the following: | | |
| | ☐ described the history, philosophy, and policies of the hospice program(s) in which the practicum occurred. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ summarized the major NHO Standards for Terminal care and any other state or local standards governing the provision of hospice care. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ identified the major sources of funding supporting the hospice care program in which the practicum occurred. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ compared and contrasted the role of the nurse in caring for the dying in the hospice program and in traditional medical settings. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ compared the model of hospice care in the local program with other hospice care models in other parts of the country. | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |
| | ☐ | ☐ | 1 2 3 ¦ 4 5 6 ¦ 7 8 9 10 |

instruction as possible. The immediacy of the practicum experience is intended to quickly reinforce the classroom learning. Those completing the whole course will thus attend two weeks of classroom instruction followed by three months of hospice practicum experience.

An alternative to the above design is for each classroom module to be followed by a practicum experience designed to further learning in the specific subject area. The practicum could thus follow completion of a module delivered as a self-contained workshop or the completion of a module via a service of one to three hour classroom sessions. The participant could complete any number of module classroom instruction/practicum experiences ranging from one to the full nine modules of the course. This allows a supervisor and the hospice nurse to design a learning program tailored to the specific learning needs of the individual.

## Supervision of the Practicum

There should be a designated supervisor to oversee and coordinate the practicum experience for each nurse completing the classroom instruction. The supervisor should ideally be located in the program in which the supervisor will be completing the practicum experience. The Practicum Planning/Evaluation Checklist at the end of Appendix A is a tool that can be utilized to plan the specific activities and demonstrated behaviors that will be expected of the nurse during the practicum. During a meeting with the nurse and the supervisor, each box is checked in column "Practicum Expectations" that coincide with the agreement between the nurse and supervisor. As these activities are completed during the practicum, they are checked off in the next column by the supervisor and also evaluated by the degree of knowledge and expertise that was demonstrated in the completion of the activity.

The supervised process should include informal discussions, skill demonstrations, and supervised demonstration of the module skill areas.

## Evaluation of the Practicum

The practicum should be evaluated using the Practicum Planning/Evaluation Checklist and by a narrative evaluation report completed by the supervisor at the end of the practicum experience.

# APPENDIX A

## Guidelines for the Clinical Practicum

### Purpose of the Practicum

The Hospice Education Program for Nurses ideally includes a clinical practicum that can provide the nurse with a supervised transition into the knowledge, skills and orientations required to provide high quality hospice care. For those nurses completing the course who have already had significant experience providing hospice care, the practicum should be designed to build on this experience rather than to focus on knowledge and skill areas that have already been mastered.

### Responsibility for Organizing the Practicum

There are at least three options as to the placement of responsibility for the clinical practicum.

In the first option, the course manager negotiates directly with hospice programs for the placement and supervision of nurses in the practicum experience. The course manager may arrange for the practicum to occur completely in hospice programs in which participants are working or may have different elements of the practicum taking place in different programs. The course manager will negotiate volunteer/practicum placement for participants who are not currently working in hospice care programs.

In the second option, the responsibility for coordination and supervision of the practicum experience rests with the Nursing Supervisor and the Inservice Coordinators from the programs that currently employ course participants. The course manager would provide these staff with suggestions and guidelines for structuring and supervising the practicum experience.

In the third option, each participant is responsible for negotiating their own clinical practicum experience. The course manager provides the participant with the practicum guidelines and each participant then negotiates their practicum in the program in which they are employed or as a volunteer in another hospice program.

### The Practicum Setting

The practicum experience must occur in a fully operational hospice program. The most ideal practicum setting is in a program that can provide both supervised, inpatient and home care experience.

### The Design of the Practicum

The practicum experience may be designed in a number of different ways. If participants completed the two week delivery of the course, the practicum experience should occur as soon after the completion of the classroom

# APPENDICES

## INSTRUCTOR NOTES

## INSTRUCTOR NOTES

## MODULE IX

## ETHICAL DILEMMA II

You are the nurse with a hospice home care program. Mrs. T. is a 34 year old mother of three school age children. Her husband is employed in middle management in a local industry. Mrs. T. has been very active as a volunteer in the community. She is terminally ill with cancer and has had two radical mastectomies and colbalt therapy. Side effects of the cobalt therapy have made her very weak. She feels that she is an increasing burden to her family since she can no longer care for her home and children. She tells you that she has considered taking her own life but doesn't have the energy to carry it out. She asks if you would help her carry out her wishes when she decides "that the time has come to end it all." She says that she knows her husband is "involved" with someone out of town. Since she is not going to live much longer anyway, she might as well end it sooner rather than later. You do not believe that suicide is ever justified and tell Mrs. T. your opinion. Then you start to wonder about your action and what you should do next.

## MODULE IX

## ETHICAL DILEMMA I

You are the nurse in a palliative care unit. Mr. R., a 66 year old former high school teacher, is terminally ill with pancreatic cancer. He has had several surgical procedures and has decided that he does not want to participate in the clinical trial of a new chemotherapeutic agent. He told you that he wants to go home "to die." He feels that his pain can be controlled at home as it has been before. He has written a "living will" which has been in his chart since he was told that he did have cancer. He has told you several times that he has a great fear of being kept alive "with all those tubes and a machine, like they did with a friend of mine." His family and physician have assured him that this will not happen to him, but he is not completely convinced and wants to return home. The local hospice has a home care service which Mr. R. can use. Since his wife died two years ago he has been living with his son and daughter-in-law. The daughter-in-law has the primary responsibility for Mr. R.'s care at home. She also takes care of two pre-school grandchildren during the week. One day she waits for you in the hall outside Mr. R.'s room. She tells you that she does not want the responsibility for caring for him again and wants him to stay in the hospital. She wants you to talk with Mr. R.'s physician about keeping Mr. R. in the hospital. She does not want you to tell anyone that she has discussed this with you. You explain to her that this is not your responsibility and that she should discuss it with the physician. She refuses. You also know that one of the hospice volunteers had some concerns as to whether Mr. R.'s care at home was adequate before this last admission. What should you do?

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | technical aspects of care of the terminally ill<br>- Models for ethical health professional/patient relationships which reflect various principles and values<br>- Framework for analyzing ethical dilemmas confronting the nurse in caring for the terminally ill<br>• The major purpose is to help nurses think reflectively and systematically about the ethical dimensions of caring for the terminally ill as distinguished from the legal and the technical |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | framework to focus discussion and asking participants to give a rationale for "opinions" or generalizations, such as "I feel..." or "There's just no doubt that..."<br>• Encourage participants to consider what should be rather than simply what exists at the present time in terms of how decisions are made. It is very easy to bog down in what exists "where I work." Point out that because something is done in a particular way does not necessarily mean that's the way it should be done or could be done. If groups want more data than is presented, indicate that frequently in the "real" world one makes decisions without all the data wished for and that the case situations are simply the basis for thinking about choices and ethical approaches systematically |
| 15 minutes | • Ask each reporter to summarize: report group's decision for the nurse in the case study and the rationale for the choice giving some examples of the group's reflections and alternatives considered by the group |
| 10 minutes | Summary of Module IX<br>• Point out that more ethical nursing practice is possible through use of the reflective thinking process used systematically in decision-making where the ethical dimension predominates. This process could be used to think through and perhaps develop some guidelines for use by nurses in the recurrent ethical situations which presently many nurses agonize about by themselves. Also indicate the need to change or modify the decision-making structures within which nursing is presently practiced to hopefully facilitate more ethical practice, (e.g., more collegial forms of practice within nursing and with other health professionals.) Some nurses already practice in such settings<br>• Mention the areas discussed in the module which reflect the objectives:<br>- Characteristics of ethical situations<br>- Distinguishing between the ethical, legal and |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| individuals may have strong feelings and hold values which influence choices. | is an opportunity to reinforce the reflective thinking process and point up the complexity of ethical inquiry<br>(Note to Facilitator: the rights-based approach is not presented in the original discussion of the framework but is introduced simply to give participants another example of an ethical approach to consider.<br>• In summarizing this part of the session, point out the technical, legal and ethical dimensions of Mr. C's situation such as:<br>- Technical - pain control and Mr. C.'s medical condition<br>- Legal - status of living will and refusing treatment<br>- Ethical - moral principles such as respect for individual self-determination and not imposing one's own values on Mr. C. and his family<br>Distinguish briefy between the more contractual and paternalistic relationship models as the nurse relates to Mr. C. and his family |
| 55 minutes<br>Handouts: Ethical Dilemmas I and II | • For small group discussion: Groups of 6-7 are generally most effective. Two case studies have been provided but participants may need the full time to work through one situation. Encourage participants to work through one situation carefully rather than hurrying through both situations. Again, the emphasis is on reflective, thoughtful decision-making and dialogue between participants as they seek to understand and clarify the situation, alternatives, ethical approaches and underlying values<br>• A group process facilitator and reporter should be selected in each group. It is important that the facilitator try to maintain the focus of the group using the framework presented as the outline for group discussion<br>• Each group should arrive at a decision for the nurse Guidelines for facilitators include using the |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | and their consideration of ethical situations and dilemmas, (e.g., obedience to authority versus self-determination) |
| | • Mention the time factor and how it varies from having to make an immediate decision in an ICU, for example, to taking time for ethical reflection on recurring dilemmas for nurses informally and individually or through more formal formats such as "ethical rounds |
| | • Show transparency again which illustrates entire framework for summary |
| | • Read case study in participant manual or have participants read the situation for themselves |
| Use transparency to show alternatives | • Ask participants for other alternatives |
| | • Discuss who should make decisions and why |
| | • Mention that in most situations there is not just one decision but several decisions which create situations in which other decisions are made, for example, whether one remains at home for terminal care or is in the hospital where different resources for care are available |
| | • Mention that decision-making is not a linear, cookbook process but the consideration of many dimensions. One then makes a provisional commitment to one course of action recognizing that given more information or different circumstances at another point in time one might take another course of action. Reflection and clarification of difficult, ambiguous decisions also allows the involved individuals to clarify and understand points of disagreement |
| Facilitator serves as role model for discussion which follows in the small groups. Emphasize reflective thinking about the situation while acknowledging that | • Go through the case study of Mr. C. with the framework and comments from the participants' manual. Present this and discuss it from the nurse's point of view. If participants disagree with some points, have them give a rationale for the disagreement as this module has as one purpose to encourage reflective thinking before taking action. Even if participants have already read the material, this |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | situations where it is unclear as to the right course of action and many aspects intersect, (e.g., the medical, legal, moral, economic, psycho-social, cultural. Also, mention that this is only one framework |
| Use transparencies to discuss the framework | ● Show entire framework first and then the parts<br>- The data base for ethical inquiry - list questions to be considered and answered as fully as possible. Mention that it is highly likely that one will not have all the information one would like to have. This is the reality of many decisions that we make |
| Provide opportunities for participants to make brief comments. Try to prevent lengthy presentation of personal anecdotes at this time, in order to maintain focus.) | - Questions that come from decision theories<br>- Moral approaches: utilitarianism, formalism, fairness<br>Describe briefly and give one limitation for each approach<br>- Limitations:<br>--Utilitarianism - interests of the individual may be overridden in considering the principle of of maximizing the greater amount of happiness for the greatest number of people or the least amount of unhappiness<br>--Formalism - principles such as telling the truth and promise keeping may conflict or one may not be able to universalize a given decision or action<br>--Fairness - different notions of justice make it difficult to decide what is most fair or just in a given situation and for whom<br>These approaches or positions do not provide answers per se, but clarify alternatives identified by the data base and their probable consequences before making decisions and taking action<br>● Show criteria for considering validity of moral principles. Discuss diverse values which nurses and patients/families bring to the care situation |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| Use transparency for presentation | - Priestly/paternalistic<br>- Engineering<br>- Contractual/covenantal<br>- Collegial<br>● Describe and discuss implications in light of constraints mentioned previously<br>● Examination of these possible relationship models and actual or potential constraints to ethical practice is significant as these constraints enhance or impede the goals of care for the terminally ill<br>● Mention Yarling's discussion of the nurse's moral right to tell the truth to terminally ill patients as an illustration of the more contractual/covenantal relationship |
| Use transparency | ● State Yarling's conditions under which the nurse can claim a moral right and under certain circumstances has a moral obligation to tell the truth to a terminally ill patient:<br>- Appropriate competence including medical knowledge of the disease and communication skills<br>- Collaboration and communication among all those responsible for a patient's care<br>- Established rapport between patient and professional which enables this kind of sharing<br>(See articles for details)<br>● In summary of this section, mention criteria which distinguish moral situations and choices from legal and technical aspects of care |
| 45 minutes | Introduction to framework for analysis of moral/ethical situations<br>Facilitator<br>● Mention again the complexity of patient care |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | - Mention limitations of ANA Code in dealing with specific situations of conflict for the nurse. |
| | Note to Facilitator: |
| | • As this is a controversial and ambiguous area and people are generally looking for "answers", it is important to state how ethical inquiry can be helpful in clarifying issues and dilemmas for discussion and resolution in a more rational, thoughtful way. Everyone may not agree with a decision or action, but will hopefully be clearer about the "why" of the disagreements |
| Use Transparency | • Distinguish between "ethical" and "technical" aspects of practice. List the four ways of characterizing an ethical situation: |
| | - Relationship in which there is conflict over the "right" action to take |
| | - Use of ethical principles |
| | - Rational choice |
| | - Choice influenced by feelings and values, e.g., religious values |
| | (See reading materials in trainee manual for more detail) |
| | Models for Ethical Relationships |
| | • Mention the nurse's position as the interface between M.D. and patient or between patient and others in the care setting and multiple sources of accountability as a constraint to ethical practice |
| | • Additional constraints include: heavy responsibilities with little power, in bureaucratic health care settings, for primary decision-making; communication patterns such as the "doctor-nurse game"; and traditional nursing values such as obedience to authority |
| | • Possible ethical relationship models of health professionals and patients according to Veatch: |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | dilemmas and the ambiguity of dealing with the ethical realm as described above<br><br>Be sure to mention that ethical and legal aspects of a situation are not identical although they often intersect in any complex patient care situation<br><br>In introducing the module, mention that the modules already presented may contain ethical issues where the nurse is in conflict about the "right" action to take in a specific situation, e.g., pain control and communication<br><br>This module gives the participant an opportunity to learn to reflect on these issues in a systematic way. Most health care professionals have not had an opportunity to do this in their educational programs, although this is beginning to change as courses in nursing and health care ethics are being instituted. Many nurses also have access to workshops which deal with general issues in applied ethics<br><br>• Introduction to ethical and legal dimensions:<br><br>- State concepts related to ethics and to law - give examples from trainee reading materials<br><br>- Ask participants for examples from their own work with the terminally ill<br><br>- State differences between ethical and legal dimensions of a situation, (e.g., "ethical" concerned with what should be related to "right" and "wrong" studied systematically and "legal" related to what is in terms of how we live together and govern ourselves in communities)<br><br>- Explain that what is legal may or may not be ethical for a specific person and situation. Although hopefully, the two are congruent, (e.g., legally a woman can have an abortion in the first trimester. This does not mean that it is ethical for a given person to have an abortion).<br><br>Another example is the use of the "living will" which is legal in some states (e.g., California) |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | NOTE TO INSTRUCTOR<br>It is important to point out at the beginning of this module that answers, per se, to ethical questions and dilemmas do not exist. They do not exist in the sense that one can go into the laboratory or to the library for the solution "once and for all."<br>Decisions and actions in the ethical realm are developed through reflective thinking, using skills which can be learned to clarify issues and dilemmas. The nurse can then go beyond a gut level feeling that something is right or wrong and can discuss the issue with others or reflect on it individually, or with others, before taking action. A decision for non-action is still a decision. Hopefully, discussion of issues and dilemmas will be done with all those involved in the situation. Also, mention that we live in a pluralistic society with diverse and conflicting values.<br>The facilitator for this module should be a nurse who either works with the terminally ill or is knowledgeable about them. The facilitator should have had at least one course in medical, nursing, or health care ethics at the undergraduate or graduate level. If the facilitator does not have minimal preparation in these areas, then a consultant should be used in the session or in the preparation for it. Ideally, the nurse-facilitator should work with a philosopher who teaches ethics and has some knowledge of the nursing profession. The nurse-facilitator may wish to present the session jointly with a philosopher. The facilitator is responsible for reading materials and working through the case studies before the presentation.<br>Facilitator/participant manuals must be used jointly by facilitator/participant. |
| 20 minutes | Overview of module and introduction to ethical and legal aspects of hospice nursing<br>● Review the objectives of Module IX with entire group<br>● Review the plan for the module<br>Highlight the complexity of ethical issues and |

A. Elucidate the date base that one needs in order to do the moral inquiry.

B. Consider the questions that come from decision theories.

C. Articulate the moral approaches, positions or theories to be used in considering alternative actions.

D. Consider the following additional components of an ethical dilemma:

1. The value systems (personal and professional) of the decision makers.
2. Time, how quickly the issue must be resolved.

E. What dilemmas can be anticipated and thought out or articulated in advance of crisis?

b. Those which have long existed, e.g., whether or not to tell the truth

II. Understanding and working with the ethical dilemmas of the hospice situation require a framework for thinking about them. Such frameworks do not provide answers, but do suggest ways of structuring and clarifying problems and our response to them.

A. Utilitarianism - focuses on the consequences of actions and on the finding of solutions that provide the greatest good or happiness (or least harm or unhappiness) for the most people.

1. This is a more community-oriented theory that may run counter to traditional medical ethics that call for the marshalling of all available resources for the individual patient.

B. Egoism - seeks the solution that is best for the self.

1. According to this framework, the nurse would choose the course of action with which he/she was most comfortable.

C. Formalism - considers neither the self nor the consequences of action, but rather the act itself, the principles or rules involved, duties and obligations.

1. An example might be the application of the principle "do unto others only that which you would have them do unto you" to the use of terminal patients in research. Such an application might well preclude such use of dying people.

D. Fairness - seeks decisions that are just and fair, that distribute the benefits and burdens in consideration of the least advantaged in a situation or society.

III. In order to consider and decide about an ethical dilemma, a structuring process must first take place that clarifies the problem and our approach to it:

# LEGAL AND ETHICAL ISSUES IN THE CARE OF THE TERMINALLY ILL

## MODULE OUTLINE

I. Care of the dying raises a number of issues for nurses: legal, ethical and technical. It is important to distinguish between these.

  A. Legal issues:

    1. Law - the rules established by authorities, societies or by custom within a community; examples: nursing practice acts, living wills in some states, e.g., California

    2. While laws establish many guidelines and practices, there are numerous situations in hospice care in which the law is unclear, undeveloped or non-specific.

  B. Ethical issues:

    1. Ethics - the general nature of ethics/morals and of the specific ethical decisions to be made by an individual - systematic inquiry into what is "right" and "good"

    2. Ethical issues in hospice care include:

      a. treatment vs. nontreatment

      b. research protocols

      c. admission policies

      d. euthanasia and suicide

      e. relationships of team members

      f. definitions of death

      g. means of pain control

    3. Nature of ethical dilemmas in health care:

      a. Those which arise out of the development of new knowledge and technology, e.g., availability of life support machinery

| | |
|---|---|
| Summary of small group discussions | 15 minutes |
| Summary of Module IX | 10 minutes |
| Total time | 3 hours |

## IV. MATERIALS REQUIRED

Resource paper: "Ethical and Legal Issues and Dilemmas in Caring for the Terminally Ill" by Mila A. Aroskar

Handouts - Case studies

Overhead projector and transparencies or flip chart and flip chart stand (These should be prepared in advance for facilitator's presentation. They can also be used for summary of small group discussions.)

## V. SPACE REQUIRED

One area for facilitator presentation and areas for small group discussions of 5-6 participants.

# MODULE IX: ETHICAL AND LEGAL ISSUES IN THE CARE OF THE TERMINALLY ILL

## I. PURPOSE

The purpose of this module is to describe ethical and legal issues and dilemmas confronting the nurse who cares for the terminally ill or dying patient and family. Use of a framework for clarifying and reflecting on ethical issues and dilemmas will be demonstrated.

## II. LEARNING OBJECTIVES

At the conclusion of Module IX, participants will be able to:

- Identify at least three ethical issues and dilemmas characteristic to hospice nursing
- Identify at least three legal aspects of hospice nursing
- Define ethical, legal and technical aspects of hospice nursing
- Identify two approaches to ethics which can be used to reflect upon the issues and dilemmas in hospice nursing
- Identify and describe at least one framework for analyzing and making decisions in situations of ethical conflict in hospice nursing
- Describe at least two models for ethical relationships of nurse/patient/families/other health professionals in hospice nursing
- Identify at least three constraints and challenges to ethical practice in hospice nursing settings

## III. CONTENTS

| | |
|---|---|
| Overview of module and introduction to ethical and legal aspects of hospice nursing | 20 minutes |
| Lecture/Discussion: description of framework for analysis of ethical issues and dilemmas | 45 minutes |
| Lecture/Discussion: demonstration of framework with case study | 35 minutes |
| Small group discussion with facilitator and recorder: discussion of case studies using framework | 55 minutes |

# MODULE IX: ETHICAL AND LEGAL ISSUES IN THE CARE OF THE TERMINALLY ILL

## FACILITATOR MANUAL

DEVELOPED BY:

Mila Ann Aroskar, R.N., Ed.D.

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INSTRUCTOR NOTES

## INSTRUCTOR NOTES

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Exhibit III-D

## LOWE/HERRANEN TEAM DEVELOPMENT PROCESS MODEL*

| STAGE | OBSERVED BEHAVIOR | EMOTIONS | PRODUCTIVITY | |
|---|---|---|---|---|
| | | | INDIVIDUAL | TEAM |
| I. Becoming Acquainted | Polite, Impersonal | Repressed, Neutralized<br>Minimal Conflict | Varied to High | Low |
| II. Trial and Error | Parallel play<br>Pairing<br>Role ambiguity resulting in overlapping of responsibilities | Suspicion, Frustration and Uncertainty | Varied | Low |
| III. Collective Indecision | Pseudo consensus<br>"Scapegoating" | Covert anger, poor team morale | Low | Low |
| IV. Crisis | Confrontation<br>Conflict<br>Delineation of roles/ responsibilities | Guilt, open anger<br>Depression | Low | Low |
| V. Resolution/Evaluation | Open communication<br>Shared responsibility with accountability | Satisfaction | High | High |

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* From Lowe and Herranen, 1978, "Conflict in Team Work: Understanding Roles and Relationships."

Exhibit III-C

## REVIEW OF INTERDISCIPLINARY TEAM MEETING

### OBSERVATION NOTES

1. What team members participated in the meeting?

2. What members were absent?

3. Did you note any confusion of role responsibilities?

4. In what areas did you observe role overlap?

5. Describe any notable areas of conflict or cooperation that you observed?

6. Who were the formal and informal leaders?

7. From your brief observations, would you say the leadership style is authoritarian, democratic, or oligarchical?

8. Did you notice any unwritten rules that governed the team's behavior in the meeting?

9. To what extent were the patient/family or the concerns of the patient family involved in the meeting?

10. How did the team meeting compare to those in your current program?

Exhibit III-B

## INTERDISCIPLINARY LOG

| Form of contact (i.e., telephone, in person, etc.) | Where contact took place, (i.e., in hallway, nurse's station, etc.) | Who initiated contact | Reasons for contact | Outcome of contact | Describe briefly your own reactions, feelings, and behavior in interaction |
|---|---|---|---|---|---|
| | | | | | |

Exhibit III-A

## TEAM STATEMENT FORM

Read each statement carefully and then write A(Agree) or D (Disagree) before question.

_____ 1. Team work ensures good patient care.

_____ 2. Patients should not be members of the interdisciplinary team.

_____ 3. Even a minor intervention with patient/family should be reported at team meeting.

_____ 4. Conflict is always destructive to team productivity.

_____ 5. Ethical and value dilemmas are best handled privately rather than at team meetings.

_____ 6. Role overlap is beneficial to team work.

_____ 7. Skills in teamwork are an innate part of each professional's training.

_____ 8. Team work implies equal status for all members.

_____ 9. Teamwork implies that members must always compromise in order to function effectively.

_____ 10. Team functioning is not possible unless all members are present.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | especially those who contribute time, money and interest.... Those planning a hospice organization must have built-in support, not merely financial, for teamwork so that in principle at least, every one involved with the hospice assumes some responsibility for reinforcing the team concept and helping with the enabling function."<br>(Rossman, 1979, p. 200.)<br>Summary of Module: The Management of Interdependence<br>● Underlying the team approach is the concept that no one individual possesses all the expertise necessary for the care of patients and families<br>● The provision of total care by an interdisciplinary team requires the participation and coordination of a variety of personnel with different resources and skills all working together towards achievement of a common task<br>● Being a team member requires an understanding of the interrelatedness of roles and functions, and the ability to break down interprofessional rivalries<br>● Teamwork is an on-going process. It requires time, effort, evaluation, and a real commitment to the interdisciplinary concept to succeed. Communication is the essential ingredient for the team approach<br>● In working together the team must learn to manage its interdependence through the cultivation of shared values, team skills and a common philosophy that transcends the individual's profession |

TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE

large group or in two smaller groups with an instructor in each group. Participants in this segment should be encouraged to be critical and analytical with regard to examining their own teams. Emphasis should be on the team group and its functioning as a unit.)

15 minutes III. CONCLUSIONS AND SUMMARY OF THE MODULE

Format: Discussion

This segment should pull together and summarize the theoretical material and experiential learning which has taken place throughout the module. Review conclusions and summary drawing from the participants the changes and/or insight they've gained in understanding team work, and in being team members. The discussion should emphasize the following:

Conclusions to Section II: Becoming a Team Member:

- To participate effectively in teamwork individuals must be aware of what it takes to do the work, what is necessary to strengthen the team, and how to effect individual and team accountability
- Inherent in the concept of accountability is open acknowledgement of individual, professional and teamwork standards
- Attractions of teamwork may obscure the issue of individual responsibility and accountability. Every problem in patient care is not necessarily one that requires the attention of the entire team. Many problems/tasks can be resolved by one or two individuals who can communicate solutions and outcomes to the larger team
- To work together successfully also requires the existence of support both within and outside the team. "People whose emotional resources are continuously drained through contact with grief and dying, without being adequately replenished, will not long be able to take proper care of dying persons or to sustain the burdens of staff teamwork. Support, however, is more than emotional support from team members. It also involves the understanding and awareness of the community,

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

Exercise 6: Analysis of Team

Purpose: To analyze from the participant's point of view the team they are part of

Utilizing the model outlined by Lowe/Herranen, select the stage that most closely approximates where the participant's team is.

Directions to Instructor

Allow participants approximately 10 minutes to study model and select stage. Participants should be prepared to give reasons for their choice.

The following questions should be the basis for group discussion:

- What is the team's level of productivity?
- How are decisions made in their team?
- Who is the leader of their team? Is there an informal leader and what role does this person play?
- What are communication patterns? Who talks to whom?
- What behaviors are seen most commonly? How are these enhancers and/or inhibitors of team functioning?
- How does it feel to be a member of a team?
- How do patients and families respond to team?
- Are there ways participants will change their own behavior in order to improve team functioning?
- What are the pitfalls to teamwork as participants perceive them?
- Is crisis in teamwork inevitable?
- How do teams move between the stages?

(Note to Instructors: This discussion can be done in a

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
|  | - Was outcome of interaction satisfactory to both participants?<br>(Note to Instructor: The emphasis in this segment is on the individual nurse's behavior and responsibility for communicating and interacting with others. It may be helpful to delineate common areas, reactions, etc. that emerge from all logs and explore if this is related to nurse's training, status, perceptions of self and others, etc.) |
| 30 minutes | II. ANALYSIS OF TEAM<br>Format: Exercise Completion and Discussion<br>• Group and individual behavior can both enhance and hinder the work of the team. The following are team building and group maintenance behaviors which facilitate achievement of goals/tasks:<br>- Encourage and solicit participation of others<br>- Decide if issues are to be dealt with by total group, subgroups, or individual members<br>- Assign and agree to priorities of goals/tasks<br>- Contribute to maintenance of task centeredness by appropriate participation and interventions to avoid threats to team productivity<br>- Assess team responsibility for outcome<br>- Evaluate team's efficiency and effectiveness in reaching stated goals/tasks<br>- Examine how team interfaces with larger environment<br>- Continue assessment of team's internal structure and process<br>By evaluating and assessing in an on-going way group and individual behaviors, the team will be better able to maintain its equilibrium through awareness of those actions which are functional and dysfunctional to productivity. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| 25 minutes | SECTION II: BECOMING A TEAM MEMBER<br>I. Interdisciplinary Log<br>Format: Discussion<br>• Individual behavior can enhance and/or inhibit working together. The following are examples of individual behavior which helps to facilitate achievement of individual and/or team goals:<br>- Identifying tasks<br>- Seeking information from and communicating with others<br>- Proposing solutions based on one's expertise<br>- Initiating activity<br>- Suggesting new ideas<br>- Ability to compromise<br>- Assuming leadership role when appropriate by coordinating and summarizing tasks to be addressed<br>- Assessing individual responsibility for outcome<br>- Providing trust and support to facilitate team's ability to do its work<br>• Ask several participants to describe an interaction from their logs. Focus discussion on:<br>- Purpose of contact both explicit and implicit<br>- Did nurse experience conflict, if so how was it managed?<br>- What problem solving skills were utilized?<br>- What was behavior of participants?<br>- Does pattern emerge in relation to the participant's method of communicating and interacting? |

module to return to their working environments.

Exercise 5: Interdisciplinary Log

Purpose: To increase the participants awareness of how they communicate and interact with other team members.

Instructions to Trainer

- Where the training schedule allows participants to return to their work settings between Section I and II, they should record on the attached log (Exercise III-B) the interdisciplinary contacts they participated in. A minimum of five and a maximum of ten interactions should be recorded
- If there is not a break between Section I and Section II, the Interdisciplinary Log should be given to participants prior to the teaching of this module. They should be instructed to complete the log drawing on their previous experiences. A minimum of two and a maximum of five interactions should be recorded
- Participants should be instructed to study their logs to see if a particular pattern of interacting and communicating emerges. These logs will be utilized for discussion in Section II

Optional Exercise 5: Review of Interdisciplinary Team Meeting

Purpose: To increase the participants understanding of interdisciplinary team roles and group behavior that can be observed in a team setting.

Instructions

During your site visit to the hospice interdisciplinary team meeting, complete the Review of Interdisciplinary Team Meeting (Exhibit III-C).

Review the completed form. How do the roles you observed differ from the role definitions within the program in which you are currently working?

beliefs, and hopes.)

Directions to Instructors

Divide the group into two smaller groups, (no more than 10-12 participants per small group).

Each small group will have an instructor as observer.

Tell the small groups to spend approximately 15 minutes on completing the task. Following task completion each group will analyze how these value dilemmas were arrived at. The instructor as observer will help the group examine how the components of teamwork were utilized in the group's process.

The following questions should be used as guidelines for each group's discussion:

- What decision-making process was utilized in arriving at the two value dilemmas?
- Did everyone participate or did one or two individuals dominate the group?
- Did a leader emerge? How?
- Was there conflict? How was this managed (i.e., fight/flight, avoidance, negotiation, etc.)?
- Who communicated with whom? Was there pairing?
- Was effort made to draw out silent members?
- If task was not completed, why?

The information given in this section of Module VIII constitutes what is operationally defined as an interdisciplinary team. Each team must take responsibility for establishing its own frame of reference and its own style of working together.

Between Section I and Section II participants should read the resource articles which are included in the manuals. They also should complete Exercise 5, Interdisciplinary Log. This exercise requires that participants have several days between sections of this

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | • The nature of patient/family participation is different from other team members in that they contribute from their own life experience and response to illness information pertinent to planning and implementing their care |
| | • Research has shown that the patient/family are more likely to adhere to and support the treatment regimen when they are involved in the management of their care and are invested in achieving goals/tasks (Hayes-Bautista, 1976; Hertz, 1976) |
| | • The following questions should be raised for discussion: |
| | - What is the most effective way of including patients and families in planning their care? |
| | - Should patient/family be a team member? |
| | - Who acts as advocate for patient/family? |
| | - What impact does patient/family participation as team member have on team functioning? |
| 30 minutes | VII CONCLUSION TO SECTION I |
| | • Exercise 4: Analysis of Working Together as a Group |
| | Purpose: To give trainees an opportunity to experience what goes into teamwork by participation in a small group. |
| | Instructions to Participants |
| | • The small group task is to choose two value dilemmas confronting the nurse in hospice care. (Value dilemmas occur when there is a conflict or tension between different ethical principles: for example, prolonging life at all costs when there is no hope for recovery vs. allowing a patient to die, or sharing patient information in team meetings vs. the patient's right to confidentiality. How team members approach these issues is a function of their individual background, |

TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE

exists a clear understanding and internalization of one's role. Confidence in one's own professional capabilities is essential to successful negotiation of role overlap

- Conflict may be attractive and challenging to some team members, making conflict the central focus rather than part of the team's natural process to be dealt with
- Resolving conflict and role overlap is an important aspect of working together in order to prevent role diffusion and team dysfunction
- Flexibility, a sense of humor, and resiliency in the face of conflict assist positively in its management

10 minutes

V. ENVIRONMENTAL IMPACT ON TEAM FUNCTIONING

Format: Discussion

The following questions should be the basis for discussion:

- What constitutes the working environment of the team? (Hospital, separate hospice institution, patient's home, etc.)
- How does the environment influence the team's functioning?
- How do policies and procedures become established and how do they relate to the team and individual's functioning?
- What environmental support systems are available to the team?

10 minutes

VI. PATIENT AND FAMILY AS TEAM MEMBERS

Format: Discussion

- The trend in health care towards greater participation of the patient/family as team members necessitates the development of their unique input

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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The role play should take approximately 15-20 minutes.

At the end of the role play place on the blackboard (or wall) one large sheet of paper for each team member played. The observer instructor will start this part of the exercise by listing one role she/he saw the nurse assume. Then the participants will be asked to contribute by identifying roles/responsibilites of all team members. These will be listed on the respective sheets of paper. The instructor will assist the participants in reviewing the posted sheets to 1) differentiate the roles unique to each team member, and 2) delineate role overlap and potential areas for role blurring and conflict.

Ask participants to consider the following questions and incorporate them into the discussion:

- How did it feel to play another professional role? Was it difficult? If so, Why? If not, Why?
- What are the specific roles unique to each team member?
- Was there conflict between the different professions? If so, Why? If not, Why?
- Were the roles of each discipline clearly differentiated?
- Where did overlap in roles occur? Did role overlap contribute to conflict?

Role Overlap and Conflict

- The complexities that make the existence of an interdisciplinary team necessary also contribute to role overlap, and thus make conflict inevitable
- Conflict and its management is the source of both the greatest strength and the greatest vulnerability to the life and the work of the team
- To work together successfully role boundaries must be differentiated yet at the same time remain fluid and flexible. This can only happen when there

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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- Ask for four volunteers to participate in the role play as the following team members: physician, social worker, volunteer, and chaplain. The role of the nurse will be played by the nurse-trainer. The other participants and trainer will act as observers. (Note: If other disciplines are participating in this segment, they should be involved in the role play. In this case it is recommended that no discipline play their own role. This enables biases, misconceptions and reality of trainees perceptions to emerge.)
- Ask trainee volunteers to take a minute to think about the role they will enact. It may be helpful to suggest to them that they model their assigned role after a physician/social worker/volunteer /chaplain they are familiar with or know
- This exercise is designed to break the didactic teaching, and provide trainees with an opportunity to participate. The role play should be fun

The following situation will be the basis of the role-play. This should be read to the entire group

> Mrs. M. is 45 years old, married and a mother of two teenage children ages 13 and 16 (a boy and girl, respectively). She has terminal uterine cancer, and has been on home care for the past two months. Mrs. M. now wants to be admitted to the hospital. The home care nurse and social worker visited the patient and family and assessed the problems to be 1) increased patient anxiety regarding her impending death, and 2) poor family communication around patient's needs. Team task is to make a plan for Mrs. M.

It is important for the nurse trainer to decide on the approach she will take to elicit different role responses. For example, she may play her role as she envisions it, she may agree with the physician only and oppose other viewpoints, or she may choose to disagree only with the social worker. It is up to the trainer to keep the exercise focused and moving.

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | Dependency also interferes with the team's work when it prevents the group from taking a risk or confronting uncomfortable feelings. Dependency can facilitate the team's group functioning when it temporarily allows the individual member or the group to take risks and move towards independence |
| | Draw from the trainees their experiences with these forms of group regression. Ask trainees to interpret from their perspectives how fight/flight, pairing and dependency enhance or inhibit the team's work as a group. |
| | ● The interdisciplinary team as a group needs to preserve its autonomy and integrity in relating to its environment |
| | ● Awareness of group process as it relates to the team's functioning enables members to diagnose group problems early, to manage them effectively, and to enhance the group's ability to work together successfully |
| 45 minutes | IV. COMPOSITION OF THE HOSPICE CARE TEAM: KNOWLEDGE AND ROLES |
| Large sheets of paper, Magic Markers | Format: Role Play and Discussion |
| | ● Exercise 3: Roles and Responsibilities of Team Members |
| | - Purpose: To elucidate the roles and responsibilities of hospice team members. (Since this is an enactment of roles, both instructors should be sure that participant biases and misconceptions of roles/responsibilities of other disciplines get covered in the discussion that follows the role play.) |
| | Directions to Trainer |
| | ● If possible other disciplines should be included for this segment of the module. This would provide trainees with an opportunity to test out their ideas and perceptions of the roles and responsibilities of other professionals involved in hospice programs |

the team often has an explicit hierarchical structure

Struggles around the issues of equality, power, control, and influence are of primary concern to the participants at different stages of the groups development

- Another important concept related to the team's group process as discussed by Bion is regression. He postulates three modes of group regression. They are:

  - Fight-Flight: This consists of either insistent angry confrontative interactions, or tuning-out, fantasy and daydreaming. The fight mode hinders teamwork when attacks are directed against specific group members or when one's own hostility gets projected to others. Teamwork is facilitated by the fight mode when open expression of conflict is encouraged and managed. The team's group process is hindered by the flight mode when members withdraw from active participation or use diversionary tactics. The flight mode can enhance the team's work by allowing for introspection to facilitate new approaches to goals/tasks

  - Pairing: This mode is characterized by expressions of support and intimacy toward another team member or the total group. Pairing hinders the group's functioning by preventing expression of conflict inherent in teamwork or by the development of antagonistic subgroups. The group's function can be enhanced when pairing allows for a supportive non-threatening environment

  - Dependency: In this mode the appeal for the group is for support and direction. There is overreliance on the leader or outside authority as well as on rules and regulations. Expression of weakness, helplessness, and inadequacy become the focus for the group's interactions with the goal/task being ignored. Dependency hinders teamwork when it prevents a member or the group from learning how to manage independently

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

(Note to Instructor: Some of this material overlaps with the content of the Components of Teamwork, and can be incorporated into that area. However, it is suggested that the following material be covered separately to emphasize the difference between the elements essential to the understanding of teamwork and the process of working together as a group.)

- All groups have observable patterns of group process. By becoming aware of the team's group process, individuals are able to enhance their capabilities as observers, participants and leaders

- In addition to the components of teamwork the following issues must be looked at in evaluating the team as a group:

  - Individual in the Group: As Kane notes, team members are first individuals, then professionals and then members of an interprofessional team

    Individuals bring to the group their unique life experience, values and perceptions of self as a member of a profession. (See previous discussion on role expectations.)

    Individual behavior in a team is a direct result of multiple factors which can be analyzed as part of the group dynamics

  - Team Size: Research has shown that the ideal team size is 6-7 full-time members. This permits the expression of conflicting views as well as participation by all members

    In large groups the interactions are more formal and controlled, unresolved differences are more acceptable, and subgroups are more common

    The size of the team group should be determined by the goal/task to be addressed, and should include all professions relevant for the resolution of the problem

  - Equality: The team as a group of equals is more an ideal than a reality: in health care settings

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|

- Norms define what is good/bad, right/wrong, acceptable/unacceptable. They influence leadership, decision-making, and communication

- Team members to function effectively need to understand how norms were arrived at and how they are enforced

- Questions for consideration and discussion are:

  --Is conflict dealt with openly or avoided?

  --Are certain subjects forbidden for discussion?

  --Are only positive feelings expressed?

  --Do all members participate in team meetings?

(Instructors should encourage participants to draw on their own experience and feelings in response to these questions. For example, what behaviors and/or professions are they comfortable or uncomfortable with? Are participants comfortable with anger?)

- Goals/Tasks

  - The goals/tasks of the team are based on its purpose--its reason for existing

  - It is easier for an individual to determine his/her goals than for a group (team) to reach a consensus

  - Questions to incorporate into this component are:

    --How are goals defined?

    --Who sets the goals/tasks?

    --How much agreement or disagreement is there among members concerning goals/tasks? How much commitment?

10 minutes — II. THE TEAM AS A SMALL GROUP

Format: Lecture and/or Discussion

meeting but in a separate meeting of the few

- Questions for consideration and discussion are:
  - --Can the team be effective in its work if leadership rotates?
  - --How is the team's function affected by struggles between formal and informal leaders?
  - --Is leadership discussed openly or is leadership assumed to be the prerogative of the physician?

- Communication

(The trainer should be aware of the content of the module on Communication Skills. Focus now should be specifically on communication within the team.)

- Sharing information is the key to effective teamwork
- How information is acquired, shared and utilized depends on the patterns of communication. For example, do roles talk to roles or is communication based on mutual trust and openness between team members
- The following questions should be raised in this component:
  - --Who talks to whom?
  - --Who is silent? Why?
  - --What are the communication patterns of the team?
  - --Is an effort made to communicate decisions to patients/families?
  - --Do team members communicate outside team meetings?

- Group Norms
  - These are unwritten rules that govern team member's behavior

TIME/MATERIALS

INSTRUCTIONAL ACTIVITIES OUTLINE

--Who has information necessary to make decisions?

--Who needs to be consulted before certain decisions are made?

--Who needs to be informed of a decision after it is made?

(Trainer may want to give an example of a problem requiring a decision, i.e.: when breaks for participants should be scheduled. This will provide an opportunity to discuss the above questions as well as the mechanisms of decision-making.)

- Leadership

  - An interdisciplinary team has a designated formal leader. In addition an informal leader(s) may emerge who also possesses power and influence within the team group

  - Ideally, leadership should be rotated to the person best qualified to help the team achieve the stated goal/task

  - The style of leadership depends on the individuals perception of self, professional identity and group process. The following are several forms of leadership:

    Authoritarian: In this form of leadership an individual uses his/her position on the team as a legitimate basis for controlling and directing the group's function. For example, a physician may control the group by limiting the exchange of information and by making a unilateral decision

    Democratic: This type of leadership encourages equal participation of all members. Also, expression of both positive and negative feelings is allowed. The team's decision-making process may be prolonged as all members may feel compelled to discuss their points of view

    Oligarchical: Leadership in this form is in the domain of a select few. Decision-making under this form often takes place not in the team

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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to reduce the dissonance, and 2) the strength of that pressure to reduce the dissonance is a function of the magnitude of the existing dissonance

- To function successfully in a team, each member must maintain an equilibrium between his/her internal values and ideas and external expectations

- The following questions should be incorporated into the teaching of this component:

  --How are nurse's professional role expectations developed? What are they?

  --Is there congruence in expectations between different professional groups? (Utilize input of non-nurse trainer)

  --In terms of team functioning what are the dilemmas in managing role ambiguity, conflict, and overload?

- Decision-making:

  - Decision-making is a necessary part of teamwork

  - How decisions are arrived at will influence the acceptance of them, and the manner in which they are carried out. For example, research has shown that team members are most likely to support what they helped to create. Thus, decisions which can be owned by the team group (and individual) are most effective

  - Different decision-making mechanisms are: decision by default (lack of group response), unilateral (authority rule), majority vote, consensus, and unanimity. What mechanism is appropriate in various situations will depend on the goal/task to be addressed, the communication patterns, and the leadership style

  - Questions for consideration and discussion are:

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
|---|---|
| | of all persons who have contact with the terminally ill." (Rossman, p. 154) |
| | • Discuss how group's individual definitions are similar to and different from those represented in the literature. Explore why this may be i.e.: the ideal interdisciplinary team vs. the reality where multidisciplinary collaboration may be the modus operandi |
| | • Let participants choose one definition they like most and discuss why |
| 30 minutes | II. COMPONENTS OF TEAMWORK |
| (Instructor decides how many minutes to each component) | Format: Lecture/Discussion |
| | Six Components of Teamwork: |
| | • Role Expectations: |
| | - Everyone interacts in a variety of roles, i.e.: mother, spouse, friend, nurse, which are influenced by internal and external role expectations. These expectations govern one's behavior as an individual, as a professional, and as a team member |
| | - Individual team members maintain their own professional identity based on knowledge and skills acquired from advanced professional education, and the understanding of how these skills can best be applied. However, studies have shown that there is little congruence between the way a profession defines its own roles and the way others define them. This incongruence between internal and external role expectations can lead to role ambiguity (expectations not clearly defined and communicated), role conflict (incompatible or conflictual expectations) and role overload (inability to meet multiple expectations) |
| | - Role ambiguity, conflict and overload are experienced as cognitive dissonance (Braga, 1972). The central hypotheses of this theory are: 1) the presence of dissonance gives rise to pressures |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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Interdisciplinary

1. Identity as a collective team supercedes individual identity.

2. Members share goals, work interdependently in all phases.

3. Members share leadership roles.

4. The interactional process is important since it effects teamwork and outcome. (From: Interdisciplinary Training Guide, National Training Directors Council, University-Affiliated Programs, Maternal and Child Health Division, Department of Health and Human Services)

- Review with the group the following four definitions:

  - Teamwork occurs when "a number of associates all subordinate personal prominence to the efficiency of the whole" (Rae-Grant, 1968, p. 4)

  - "A team is a group of people each of whom possess particular expertise; each of whom is responsible for making individual decisions; who together hold a common purpose; who meet together to communicate, collaborate and consolidate knowledge from which plans are made, actions determined, and future decisions influenced." (Bloom and Parad, 1976)

  - "An interprofessional team is a small organized group of persons, each trained in different professional disciplines, and possessing unique skills and orientation among whom there is an organized division of labor around a common problem, with each member contributing his/her own talents, with continuous intercommunication, reexamination and evaluation of individual efforts in terms of limitations provided by team goals and objectives, and with group responsibility for the final outcome." (Kane, 1975, p. 3)

  - "The interdisciplinary team in a hospice draws together and coordinates the planning and work

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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|  | definitions of an interdisciplinary team will evolve from participants previous experience, observations, and personal/professional belief systems. Therefore, the participants are asked to complete these two exercises prior to any other discussion of the module. |
| 10 minutes | • The instructor should review with the trainee group the introduction, purpose, content, and learning objectives as stated in the Module VIII manuals. Answer appropriate questions. |
| 15 minutes | Section I: OVERVIEW OF INTERDISCIPLINARY TEAM CONCEPTS |
| Blackboard | Format: Discussion |
|  | • Ask participants to look at their definitions of an interdisciplinary team. Have several participants read their definitions to the group. While they are doing this write on blackboard key words that emerge from these definitions i.e., collaboration, coordination, respect, professional identity, overlap, conflict, etc. Discuss how they arrived at their definitions. Look at positive and negatives involved in definition |
|  | • Differentiate between collaboration (i.e., can be done with one or two disciplines outside team) and teamwork (i.e., working together as a group). Note that collaboration does not necessarily imply teamwork. The following may be used to delineate this further: |
|  | Multidisciplinary |
|  | 1. Individual professional identities are more important than team identity.<br>2. Members share information.<br>3. Highest ranking member is team leader.<br>4. The interactional process is irrelevant since the team is not the primary vehicle for action. |

| TIME/MATERIALS | INSTRUCTIONAL ACTIVITIES OUTLINE |
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| | Note to Trainer: The content and exercises presented in this module are designed to integrate theory with practice. The trainers should be familiar with the four articles included in the module. Further, the book Team Building: Issues and Alternatives by William Dyer is recommended as an additional trainer resource. The active participation of both instructors and participants is required for optimal learning experiences. There are overlapping areas within the module which present the interrelatedness of various frameworks and concepts. Further, some of the material presented also relates to other modules, and where appropriate, reference should be made to those. The final decision for teaching this module, particularly the use of the exercises, rests with the instructors. |
| 5 minutes | I. INTRODUCTION EXERCISES AND OVERVIEW OF MODULE |
| Team Statement Form | ● The session should begin by asking participants to turn to and complete Exercise 1, Team Statement Form. This exercise will serve two purposes:<br>- to introduce the participants to some of the concepts to be duscussed in this module<br>- to give instructors the opportunity to assess the group's current perceptions regarding teamwork<br>Upon completion of these statement forms the participants will 1) collect them, 2) review them at a later time, and 3) incorporate them into group discussion throughout the modules (i.e., statement 2 "Patients should not be members of the interdisciplinary team" can be raised as an issue for discussion in the segment on patient/family as team members). |
| 5 minutes | ● Participants are next asked to turn to Exercise 2, Definition of an Interdisciplinary Team. Instruct participants to write their definition of teamwork on a blank piece of paper. Allow participants to keep this exericse for discussion later in the module.<br>Agreement or disagreement with team statements, and |

- Several flip charts or large sheets of paper that can be attached to the wall
- Five or six magic marker pens
- Blackboard in the large room with chalk

## INSTRUCTIONAL ACTIVITY SEQUENCE

| Content | Time |
|---|---|
| Section I: OVERVIEW OF INTERDISCIPLINARY TEAM CONCEPTS | |
| Introduction Exercises and Overview of Module | 20 minutes |
| Definitions of an Interdisciplinary Team | 15 minutes |
| Components of Teamwork | 30 minutes |
| Team as a Small Group | 10 minutes |
| Composition of a Hospice Care Team: Knowledge and Roles | 45 minutes |
| Environmental Impact on Team Functioning | 10 minutes |
| Patient and Family as Team Members | 10 minutes |
| Conclusion to Section I: Analysis of Working Together as a Group | 30 minutes |
| TOTAL TIME: | 2 hours 50 minutes |
| Section II: BECOMING A TEAM MEMBER | |
| Interdisciplinary Log and Discussion | 25 minutes |
| Analysis of Team Discussion | 30 minutes |
| Conclusion and Summary of Module | 15 minutes |
| TOTAL TIME: | 1 hour 10 minutes |

The detailed instructional activity sequence for Module VIII is displayed on the following pages.

Ideally, the trainee group should be interdisciplinary. It is recognized that this is not always possible, and thus this module has been designed so that optimal learning can take place in a single professional group. Through a combination of lecture, discussion, and individual/group exercises this module will present a basic framework for interdisciplinary team work. The module is divided into two sections: I. Overview of the Interdisciplinary Team Concepts, and II. Becoming a Team Member. The first section consists of theoretical information necessary for understanding teamwork. Interwoven with the theory are exercises designed to enhance the participant's integration of this material. The second section is aimed at helping the participants develop an awareness of their own roles and functions in teamwork. Further, the exercises in this section will provide the participants with practical tools for analyzing and critiquing their team as well as teamwork in general.

This material can be best integrated by the participant if there is a time break between teaching Section I and Section II. When there is such a break, Exercise 4 can be utilized to apply the learning in Section I in the setting in which they are working. Where the training schedule does not allow for such a break, optional Exercise 4 can be substituted.

## V. STAFF REQUIREMENTS

A minimum of two instructors are required for the teaching of this module. To facilitate participant learning, it is mandatory that the instructors belong to different professional groups. It is recommended that the two instructors work jointly sharing responsibility equally. This would allow the trainers to be role models providing concrete examples for the participants. If this is not feasible, another approach would be for one instructor to assume the major teaching responsibility having the other participate only in those segments where two instructors are designated. It should be remembered in making this decision that the focus is on working with other disciplines, and on understanding behavior(s). Instructors must be willing to look at their own modes of interacting as well as their assumptions and biases towards interdisciplinary teamwork.

One instructor must be a nurse (minimum M.S. prepared) with adequate clinical experience in group work and as a team member. The second instructor can be a social worker (minimum M.S. prepared), psychologist, or physician with previous experience in group and teamwork. In addition, it is suggested that one instructor have experience in hospice care or in work with chronically or terminally ill patients and their families.

## VI. SPACE REQUIREMENTS

Two rooms are necessary: one large enough to contain the total group, one smaller for 10-12 people. In order to maximize contact and learning, chairs should be provided with writing tables and arranged in a circle.

## VII. MATERIAL NEEDS

- Four * articles from the bibliography

e. Identify four group norms observed in the hospice care team

f. Describe how goals/tasks evolve at a team meeting

- Describe and discuss group behavior that can be observed in a team setting
- Describe and discuss the roles of hospice team members. Identify and draw conclusions about areas of overlap between members
- Interpret and discuss the role of conflict as it relates to group productivity and goal outcomes
- List and describe four ways the hospice environment effects team functioning
- Describe and critique the role of the patient and family as team members
- Discuss and critique value dilemmas encountered by the nurses on hospice care teams
- List and discuss three individual behaviors which enhance and inhibit team work
- Utilizing one interdisciplinary interaction the participant has been involved in, analyze and assess his/her own behavior and reactions as a team member
- Describe and analyze the hospice care team from the trainee's perspective utilizing the team model by Lowe/Herranen

## IV. PERSPECTIVE

This module is based on several premises. The first is that teamwork is a continuous process. A team often develops a life of its own, and thus ongoing evaluation of the team's work is essential. Team members must share a common philosophy and framework for working together in order to achieve the stated goals/tasks. They must be willing both as individuals and as a group to examine the group's process, the level of task achievement, and the impact of the team's work on patients/families. Second, paramount to effective team work is the understanding of conflict. Team members must be capable of viewing conflict as both an enhancer and inhibitor. Conflict is inevitable when different professionals with a variety of perspectives and assumptions are brought together in a group. Therefore, it is important for team members to possess a thorough understanding of their own professional practice and skills as well as an appreciation of the knowledge and functions of other disciplines. Finally, as in any circumstance where people work together, different personalities emerge. Team members must develop a sensitivity to and respect for each other that values differences as well as similarities.

# MODULE VIII: INTERDISCIPLINARY TEAM

## I. PURPOSE

The purpose of Module VIII is to develop a fremework for interdisciplinary team concepts which will enhance the nurse's understanding of and participation in the hospice health care team.

## II. CONTENT

The module content includes the following areas:

- Operational definitions of an interdisciplinary team
- Components of teamwork
- The team as a small group
- Composition of the team in the hospice care setting: Knowledge, Roles, and Conflict
- The environmental impact on team functioning
- The patient and family as team members
- Process analysis of participant's individual participation in working with members of the interdisciplinary team
- Process analysis of the hospice care team utilizing the team development model by Lowe/Herranen

## III. LEARNING OBJECTIVES

At the end of Module VIII participants will be able to:

- Describe two definitions of a team
- Discuss the components of teamwork as follows:
    a. Discuss internal and external role expectations as related to the hospice nurse
    b. List and describe three types of decision-making that influence team functioning
    c. List and discuss three different leadership styles that influence team functioning
    d. Identify communication patterns most prevalent in hospice care team, and discuss the impact of these patterns on goal/task achievement

# MODULE VIII: INTERDISCIPLINARY TEAM

## FACILITATOR MANUAL

DEVELOPED BY:

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